THE EFFECTIVENESS OF DOING GRIEF WORK WITH CHILDREN: AN EXPLORATORY STUDY

by

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Abstract

This study aimed to evaluate the efficacy of a group intervention with 12 bereaved children, aged 8-12. All of the children had been bereaved of a parent within the past 2 years. Due to the small number of children available for inclusion in the study, 6 of the children had previously received individual professional help for grief related issues. The design was a repeated measures pre and post intervention between group design. The study compared the two sub-groups of bereaved children with a group of non-bereaved children who were matched in terms of age and sex.

The results indicate that the behaviour of bereaved children was different to that of non-bereaved children. The behaviour of the bereaved children significantly changed following the intervention, becoming more 'normalised'. The somatization sub-test showed the most behaviour change. A bereavement was not shown to affect the acquisition of the 'concept of death' in this age group, as this knowledge was almost complete prior to the intervention. However the bereaved children did hold different views about what happens to someone after death, and tended to predict an earlier age of mortality than the comparison children. The results also suggested that the parent and child grief reactions mirror each other. Insufficient data may have prevented this pattern from achieving statistical significance. The children and their surviving parents felt that the intervention was beneficial.

Future research should include pre-disposing contextual factors in the analysis. These studies would enhance our understanding of those factors which increase bereaved childrens' vulnerability to emotional difficulties, and those which prevent their adaptive coping. Longitudinal research designs could investigate what constitutes 'recovery' from bereavement. They could also investigate whether a preventive psychoeducational intervention, such as the one outlined, decreases the incidence of emotional difficulties in later childhood. A future proposed service development is outlined.

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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Clinical Psychology has the author been registered for any other University award.

The contents of this bound volume are identical to the volume submitted for examination in temporary binding except for the amendments requested at the examination.

This study was conducted whilst the author was a Trainee Clinical Psychologist in the South West Region based in the Severn Healthcare Trust, and the research was conducted in collaboration with the Gloucester Royal Hospital Acute Unit.

Signed .....

Date 2/12/93.

Chapter 1

Introduction

The introduction will start by describing the demography of parental death in Britain today. Then the various psychological theories of grief will be discussed in general, and then more specifically as applied to grief in children. The evidence available in the literature for children grieving is then presented, followed by a description of the grief reactions typically found in this client group.

As with adults, children's grief is affected by many factors, some of which are expanded in the text. The literature relating to current services available for bereaved children is then reviewed and more formal evaluation studies with this client group are reported and commented upon.

Having established the context of bereavement work and research with children, the rationale for the current research is outlined.

1.1 Demography

Although many people will not be bereaved until they are young adults, or in their middle years, about 200,000 children, 1.6% of all children under 16 years in England and Wales have lost a parent by death (Finer, 1974). Nine percent of one parent families with dependant children are due to the death of one of the parents (Key Facts, 1993).

It is an inevitable fact of life, that we shall die. In the earlier part of the century death was more visible, with the average life expectancy of men and women being 44 and 48 years respectively (Carr, 1981). People typically died at home, with the whole family paying their respects to the body and taking part in the numerous rituals surrounding death. Due to medical advances, the fatal conditions of the present day, are those associated with longevity. Deaths at the present time "have become unfamiliar events, that take place in unfamiliar surroundings, watched over by unfamiliar people" (Carr, 1981,p.138). 'Death' is perhaps the last taboo in society today.

1.2 Models of grief

Much has been written about the process of bereavement following the death of a loved one (e.g. Parkes and Weiss, 1983). That we should feel sad and depressed is understandable, but many aspects of grief such as anger, active searching and yearning and reports of the continued 'presence' of the deceased person,

challenge our understanding of grief. Grief 'models' have tended to focus on either the emotional reactions to loss ('depression' models), or on the health consequences of such a loss ('stress' models), (Stroebe and Stroebe, 1987).

The depression models conceptualize the loss in different theoretical terms. The classic psychodynamic model (Freud, 1917/1957) views grief in terms of the need to sever ties with the deceased to regain the emotional energy invested in them. This model was influential in proposing that the painful process of grief served an important psychological function for the bereaved. However it has been argued that Freud's description of the cathexis fails to include such interpersonal influences as the social environment and the need of the bereaved to talk about their loss and receive condolence and support in this process. The 'attachment and loss' model (Bowlby, 1982) rectifies this omission, by integrating the ideas from psychoanalysis and ethology. This theory attempts to explain the paradoxical symptoms of yearning, anger at desertion and the feelings of 'presence' of the deceased, which may be present in the 'protest' stage of grieving, by emphasizing the biological survival aspects of attachment. However in the case of permanent separation, as exemplified by death, this biological 'secure base' response of active searching and yearning is viewed as dysfunctional, thus the theory has little to offer about the psychological function of grief. The 'extinction' metaphor in the behavioural model proposed by Lewinsohn et al,(1979) views grief as the painful and frustrating process of a significant reduction in positive response-contingent reinforcement, as the reinforcer has

died. Also previously reinforcing activities may be associated with the deceased and thus their reinforcing abilities are reduced. The death of a loved one is also likely to be associated with an increase in aversive events. This model would predict grief as being more intense when the relationship had been happy, as oppose to ambivalent, which is inconsistent with psychoanalytic theory. The purely behavioural model is unable to account for the different reactions of an individual under similar schedules of reinforcement, such as during temporary separation, as opposed to death. A cognitive-behavioural model can offer an explanation for these differences and the reactions more commonly associated with the 'despair' phase of grieving, such as apathy, loss of appetite and withdrawal.

A cognitive approach to grief was proposed by Abrahamson et al (1978), who reformulated the learned-helplessness model (Seligman, 1972) from a learning perspective into an attribution theory. Unlike the original model the theory is not related to loss of control per se, but the attributions individuals make in order to make sense of the event. Attributions are made along three dimensions of characteristics; universal - personal, stable - unstable and global and specific. This model suggests that people become more depressed when they perceive that undesired outcomes are personal, stable and global. Thus, the causal attributions that individuals make about the death, may affect the course of their grieving. If the bereaved blame themselves for the death, or not preventing the death, however irrational this may be, this personal rather than universal causal attribution may lead to loss of self-

loss of self-esteem and guilt, which may be particularly relevant after a death by suicide (Parkes and Brown, 1972). It also may be particularly prevalent in the case of bereaved children, who do not have the available information to make accurate causal attributions. The pervasiveness and chronicity of their grief will depend on the globality and stability of the characteristic seen as causal. This model is also helpful in explaining why ambivalent relationships, where bereaved individuals may perceive. that they contributed to the death in some way, may increase the risk of complicated grief reactions (Parkes and Weiss, 1983).

The above models contribute to our understanding of the emotional symptoms of the grief reaction. The stress models perceive grief as a major stressful life event. The physiological and psychosomatic work has been incorporated into the general psychological stress model (Lazarus and Folkman, 1984) which can account for individual differences in grief reactions. It attributes these to the relative demands of the situation and the different coping resources, both internal and external, which individuals have access to in order to deal with the life event.

Despite the usefulness of these models in providing the theoretical explanations for some of the experiences of grief, they are limited in their ability to guide clinical interventions in work with bereaved individuals. In contrast to these models, other models have conceptualized grief as a 'process', composed of stages (Kubler-Ross, 1969). The stage model has often been misconstrued as a stepwise guide to the grieving process. It was assumed that grief progressed in a neat linear order, thereby lending itself to

over-simplification. The notion of describing the grieving process in terms of a series of phases which the mourner must pass through, has been postulated by other workers (Parkes, 1970; Bowlby, 1980), again with the proviso that these were seldom distinct, and the order may vary between individuals. Although these descriptions of grief appear valid, they imply a certain passivity, an inevitable journey that the bereaved must complete, and they cannot easily be translated into specific intervention strategies. Perhaps a more clinically useful conceptualization of grief is as a series of 'tasks' (Furman, 1974; Worden, 1982). Such models embody the notion of 'active grief work', implying that the grief process can be influenced by intervention and can be helped by the bereaved individual accomplishing the necessary tasks. This approach may counteract some of the helplessness that many bereaved people experience. However, it is not a way of shortening the grief process, but can be used to develop strategies in order to focus and direct the process, to ensure that all of the psychological issues have been addressed and accomplished.

Such task models have more recently been adapted and applied to the grief process of bereaved children (Baker et al, 1992). It addresses cognitive and contextual issues specific to this client group. In Baker's "time-related" (1992) model, 'tasks' are viewed as time-limited, in that the particular tasks that are required of the individual change over time. This is a somewhat misleading notion, as the psychological tasks which need to be addressed are not related to the actual time since the bereavement per se, but to the individual's position within the grief journey and the developmental

tasks and transitions which they face. Early tasks begin as soon as the child learns of the death. They involve gaining a full understanding of the meaning of death in general, and the nature of the particular death which has left them bereaved, whilst retaining their self-protective mechanisms to guard against the full emotional impact of the death. Middle-phase tasks include accepting the loss and re-evaluating the relationship with the lost love object into an internal attachment, whilst gradually bearing the intense psychological pain involved. Late tasks are concerned with the consolidation of the child's identity and significant relationships in his life and a resumption of progress on age appropriate developmental issues.

1.3 Do children grieve?

There has been considerable controversy over the years as to whether or not children are capable of mourning. Psychoanalytic schools of thought present an almost unanimous position that pre-adolescent children don't grieve, as this requires the operation of ego functions to which the child doesn't have access (Wolfenstein, 1966); Rochlin, 1965). This stance goes on to state that the response of children to the death of an emotionally significant person, "assumes a pattern which is strikingly similar to pathological forms of mourning as seen in adults" (Miller, 1971, p.701). Instead of "detaching the survivors hopes and memories from the dead" (Freud, 1913,p.65), the reactions to loss in children are seen as having a contrary aim, "to avoid the reality and emotional meaning of the dead and maintain, in some internal form, the relationship that has been ended in external reality" (Miller, 1971, p.701). However, other writers have expressed the view that the continuation of an internal attachment to the lost person is common in normal bereavement (Glick et al, 1974; Shuchter, 1986) and may be a sign of healthy recovery, not of pathology (Baker et al, 1992).

In contrast to the psychoanalytic stance, some authors propose that children experience the loss of a prime attachment figure from as early as 6 months of age (Bowlby, 1960), although this is indistinguishable from their reaction to extended separation, as the infant has no concept of time. If good quality nurturing is provided from an undistressed substitute care-giver, then no long term effects are present. Furman (1974) proposes that children

truly mourn from the age of 3 years when object constancy has been achieved. The young infant experiences the death in terms of separation, absence and then protest, despair and detachment as vividly described by workers such as Bowlby.

The main controversies in the literature on the issue of whether children grieve, centre around the necessary cognitive development which needs to be attained before children's understanding of death is sufficiently advanced for them to grieve. A full comprehension of the concept of death would make it easier for children to understand the loss of a loved one, but the lack of this doesn't negate grieving, it simply means that the children must assimilate the information they have to explain the fact that their parent has gone (Furman, 1974). This inadequate knowledge may merely increase the children's employment of fantasies and magical thinking to fill in the gaps in their understanding and produce more difficulties in their grieving, self-esteem and subsequent attainment of developmental tasks.

Parents occupy a unique place in the centre of the child's universe, with young children in particular investing almost all of their emotional energy in their parents. Poor adjustment to a bereavement has been associated with problems such as school refusal, depression and phobic reactions in childhood (Caplan and Douglas, 1969; Black, 1974). It has also been linked to an increased vulnerability to psychiatric disorder in later adulthood (Brown et al, 1977). The most comprehensive study of bereaved children to date (Elizur and Kaffman, 1982, 1983; Kaffman and Elizur, 1979, 1983) showed that 39% of the children, who had all lost their

fathers, showed problematic bereavement reactions at 42 months post bereavement. Interim results from an ongoing larger study by Silverman and Worden (1991), revealed that 20% of the children remained very distressed at 25 months post bereavement.

Although the various authors are are not agreed as to whether the child's experience equates with an adult's conception of grieving, there is agreement that the loss of a parent during childhood is a profound psychological trauma that threatens the child's social and emotional development (Osterweis et al, 1984). Silverman and Worden (1991) suggest that children do grieve, but this differs from adult loss in that children continually renegotiate their loss experience as they grow and develop, particularly at significant times, such as puberty, first relationships, weddings, and when the child reaches the age of the parent when he/she died. These workers purport that the grieving process experienced by children, may be longer than that of an adult due to their limited coping strategies. Indeed previous research has shown that disorders, if they occur, develop some years after the bereavement. Rutter (1966) found an average gap of 5 years between the bereavement and the onset of symptoms in one third of his clinic sample. These results are confirmed by the 'disaster' literature, with Terr (1983) finding that the child victims of a bus kidnap were "profoundly affected...4 to 5 years after the trauma". This long delay between the bereavement and subsequent onset of symptoms raises the issue of intervening variables which may modify the child's reaction to the death of a parent.

1.4 How do children grieve?

Children, like adults, do not react in one specific way to the death of a significant other. Raphael (1983) has summarized 'normal' grief reactions in children of all ages. These reactions differ from adult grieving and vary with the age, cognitive development and personality characteristics of the child. Young children generally fear further abandonment and suffer insecurity. They may not comprehend the irreversibility of death and so may attribute causitive factors for the disappearance to themselves. For example, the child may have misbehaved prior to the 'disappearance' of his Dad. When his Dad is reported as dead and fails to return, the child may think that he is so naughty he has driven his Dad away. Some workers (Nagera, 1970) note that children of about 5-8 years may use denial as their coping mechanism in the event of loss. Although their overt response is one of being unaffected, the inner lives of children may be in turmoil. Children may not ask for explanations, but maintain their denial and construct fantasies to keep the relationship with the dead person alive (Raphael, 1983).

Older children not only have an adult understanding of death, but also an understanding of their own mortality and future. They are likely to have established relationships outside of the home, and may experience a more ambivalent relationship with their parents which may generate more guilt, or idealization of the dead parent during their grief, and jeopardize resolution of the loss.

There are a variety of immediate reactions and later expressions of grief. The most common immediate reactions are,

shock and disbelief, dismay and protest, apathy and being stunned or a continuation of their normal activities. These reactions typically protect children from becoming emotionlly overwhelmed and allow them to absorb the news gradually, thus helping them to cope initially with such an extreme situation as a parental death. Other reactions then follow, which may include a variety of symptoms.

Anxiety

According to Dyregrov (1991), this is a common reaction of children to the loss of security, more typically centred as a fear that something may happen to their surviving parent or carer. Fear for their own mortality is more common if the bereaved are in adolescence, (Dyregrov, 1991). Often children demonstrate their anxiety by becoming more clinging and demanding, and resisting separations from the parent. This may be more evident at bedtime and lead to sleeping problems, or other separation difficulties such as school refusal, (Black, 1978). Hypersensitivity may be shown, which is more related to the traumatic nature of the death, (Pynoos and Nader,1988). This can lead to muscular pain, tension headaches, lack of concentration and subsequent difficulties with schoolwork.

Vivid Memories

Images can 'fasten' in all senses and form strong memories. This again is often related to trauma and has been reported in the literature regarding survivors (Terr, 1983). These images leave a lasting impression and often haunt the child in the form of intrusive memories, which again hamper concentration, or in nightmares.

Sleep Difficulties

These may be related to anxiety, and the increased opportunity to think about what has happened when alone in bed. Children may resist sleeping alone, request that the light be left on or the door opened and a parent stay with them until they are asleep. The sleeping difficulty may be exhibited as a difficulty in falling asleep, or frequent waking, which may be associated with dreams or night terrors, often referred to as nocturnal anxiety attacks (Herbert, 1992). In Arthur et al's (1964) study of bereaved children, 23% reported night terrors. This tends to be more of a problem if 'sleep' has been used to describe the state of the dead parent (Raphael, 1983).

Sadness and longing

This may be shown as inconsolable grief, although children may tend to withdraw and isolate themselves, fearing loss of control, or internalizing parental demands for containing feelings, or identifying with parents' own ways of handling their emotions (Furman, 1974). Children often try to hide these feelings from the surviving parent, so that they don't make their parent sad. Sadness and longing are felt more acutely when situations arise when they see other children with both parents, or when they are differentiated from the other children, such as making Mother's Day cards at school, when they no longer have a mother (personal communication). This may also be displayed in active searching behaviour, or a desire to talk about their dead parent or study photographs and a need to keep them close by, keeping a favourite item of the deceased with them (Dyregrov, 1991). Children's

different ways of seeking closeness with the dead person reflect the pain of letting what is lost go, and helps them to take in the loss step-by-step. Children may also experience hallucinations, where the dead person is seen or their presence felt, which may produce more anxiety as they feel that they are bordering on madness.

Anger and acting out

Anger may be directed at many things; against God for letting the death happen, or for taking the parent if the child was given such an explanation. Anger may be directed at adults for excluding the child from their grief or at others and/or themselves for not preventing the death. Children may be angry with those they hold responsible, or at the dead parent for deserting them, especially in the case of suicide (Dyregrov, 1991). Anger may be in the form of temper tantrums or a rebellion against authority. It seems to be a more common reaction in boys, who have more difficulty in expressing their emotions (Dyregrov, 1988), but this may be because society accepts the behaviour more from them. Acting out may be a way of keeping the sadness and depression at bay.

Guilt, self-reproach and shame

Based on the knowledge of children's egocentric and magical thinking, children may be more susceptible to thinking that their thoughts, behaviour or feelings contributed to the death of their parent (Raphael, 1983). This may also be related to regrets for things that the child never got to say to the parent. The child's presence at the death, and the type of death may affect the amount of guilt the child feels.

School problems

Children dealing with crises of death or separation show greater overall school maladaption than children without such histories (Felner et al, 1981). Difficulties in attention, concentration and intrusive thoughts may affect the child's school performance, as will sleeping problems if they persist. In Silverman and Worden's (1993) study of bereaved children, 37% reported that they had some difficulty concentrating in school. The routine of school is often essential in restoring some form of control on the chaotic world of bereaved children and has the potential to provide comfort and support to the child. However, often the childrens' poor performance and teasing by peers, experienced by 14% of bereaved children in Silverman and Worden's (1993) sample, make this environment very aversive for them. School problems often persist for over a year post-bereavement and have not received adequate attention to date (van Eerdewegh et al, 1985).

Somatization of anxiety

Children may report an increase in muscular pains or headaches (Dyregrov, 1991), but also they may report symptoms similar to those of the deceased, which may cause great concern for the whole family, such as persistent abdominal pain in children following the death of a family member from leukemia (Binger, 1973). Seventy percent of the children in Silverman and Worden's (1993) study reported somatic symptoms, significantly more ($p<.001$) than their matched non-bereaved controls

Regressive behaviour

Children of all ages may show various forms of regressive

behaviour. Younger children, particularly girls, show an increased tendency to wet or soil compared to non-bereaved children of the same age and sex (van Eerdewegh et al, 1982) and become more clinging. Older children too may seek the closeness of the remaining parent. These symptoms exact great demands on the parent who is often also struggling to cope.

Pessimism about the future

This may be the root cause of a child who changes from an optimistic out-going child to a more pessimistic personality. Children who loose faith in their own future have been reported in the literature on major disasters (Terr, 1983; Dyregrov, 1987).

Fantasies

If these develop, they are often based on misconceptions about the circumstances of the death, due to the limited information provided by adults (Dyregrov, 1992). Often children will re-enact the death many times in play, which may be the child's way of working through it.

Maturity and growth

In the longer term, if children cope well with the loss of a parent, the resolution of this stressful situation will strengthen their ability to cope with other stressful events in the future and according to Offer (1969), can provide the potential for growth.

1.5 Factors which affect grief reactions in children

1.5.1 Children's understanding and concept of death

It has been established that even very young children are aware of death. For example, all of the three year old children in Kane's (1979) study were able to recognise a picture of a dead unmutilated rabbit from a selection of pictures of rabbits in various states of activity. Children experiment with alternating states of being and not being, as played out in the game 'peek-a-boo' (Maurer, 1966). Misconceptions in understanding may be exacerbated by semantic pitfalls in the English language, such as being a 'live' wire, the telephone being 'dead' and the hills becoming 'alive' with the sound of music.

A notion of the concept of life is presumed either to precede the development of the concept of death, or to develop alongside it (Safier, 1964). Piaget's cognitive - developmental stage theory has been applied to the concept of life and supported by Russel (1940), and it was using this stage theory framework that the early researchers (Anthony, 1940; Nagy, 1948) based their descriptive studies of the acquisition of the concept of death in children. These studies seemed to confirm the Stage Theory, with children gradually gaining a more 'mature' understanding with increasing age. Nagy's suggestion that children reify death may have been a culturally specific finding as it has only been replicated in one further study (Lonetto, 1980). In Lonetto's work the demand characteristics inherent in the concrete nature of the drawing task may be responsible for this finding, rather than it

being spontaneously generated from the children.

A more flexible interview and discussion approach was used by later researchers, who moved away from the stage related approach of the development of the concept, to that of studying the acquisition of the constituent components of the concept. Koocher (1974) asked 'What makes things die?' looking for an appreciation of causality, and 'How do you make dead things come back to life?' for an understanding of irreversibility. She also asked the children at what age they thought that they would die and what would happen to them after they died. Her results again supported the notion of a general accumulation of components and a move from concrete to abstract thought processes with increasing chronological age. Further work introduced components in more detail (Kane, 1979; Reilly, 1983) and confirmed the earlier conclusions that the nodal point in conceptual development is about 7-8 years old, although almost a third of the 5 year old children in some studies, (Lansdown et al, 1985) had a virtually complete concept and were able to discuss death. Kane(1979) explained her results of the acquisition of components in terms of inferred stages of cognitive development as defined by Piaget and as a function of age. The youngest children, aged 3-5 years tended to view death as a description of another state of being, like sleep, where the dead person is immobile and separate from other people. There is little understanding of it being a universal and final process, but rather as a continuation of existence in changed circumstances, where there may be a possibility of ressurecting the person to life again if the correct measures are taken, such as

"praying". At this level the childrens' thinking is egocentric and magical. Children between the ages of 6-8 years have some knowledge of all of the components of the concept of death. It is viewed as inevitable and universal, although the children do not perceive this as being particularly personally relevant as they view death as a part of old age and consequently very far away. The main difference between this age group and older children is that the later usually see death as an internal biological disfunctionality rather than attributing it to external causes.

Despite the majority of literature associating the development of the concept of death with age and cognitive development, particulary verbal skills (Jenkins et al, 1985), Stambrook and Parker (1987) point out that the individual differences which are apparent in all studies imply that other factors may contribute and facilitate an understanding of death, the most obvious of which would be experience with death. Previous research considering the effect of experience on the rate of acquisition of the various components of the concept have produced contradictory results. Kane(1979) found that experience of death of a close relative contributed to a more mature understanding of death in relation to that of inexperienced peers of children under 6 years of age only. She concluded that experience had little effect on the older children as their knowledge had already reached a 'ceiling' level. However Bolduc (1972) found that experience was advantageous to the development of the concept in 9-14 year olds, whilst other researchers (Tallmer et al,1974; Jenkins et al, 1985), studying 3-9 year old children, found no significant differences attributable to

experience. A more recent study (Cotton et al, 1990) was inconsistent with the previous research, finding a negative correlation between death experience and accurate death concepts. This anomolous result may be explained by the sample of children being drawn from a bible class. It could be argued that they may differentiate between the finality of death, and the continuing spiritual after life, but may not have made the distinction explicit. These mixed results may be attributable to different measures of the concept of death employed in the studies, or different participant characteristics, but it is more likely to reflect the researchers definition of 'experienced', which when specified ranged from significant others to non-intimates and the death of pets.

Religious themes or orientation are infrequently reported in the literature on the understanding of death in children, but are likely to influence the childrens' responses. Childrens' comprehension of the rituals surrounding death have also received scant review. As part of this study the effect of the death of a significant other on the childrens' development of the concept of death, their own mortality and their understanding of the rituals surrounding bereavement were studied. There is no doubt that the childrens' level of understanding affects their own grieving process.

1.5.2 Type of death

Deaths are usually categorized according to 'NASH' (Worden, 1983), which stands for 1) natural, 2) accidental, 3) suicide and 4)

homicide. The type of death typically reflects the timeliness and trauma involved and therefore affects the information communicated to children in terms of preparedness for the death and details about what happened. The type of death can also be broadly defined as being expected or unexpected.

Expected

The anticipation of a parent's death, during the terminal phase of illness, may help the surviving family members to address the reality of the loss prior to it actually occurring, and may make the grieving process easier. This period may be adaptive, in that open communication may aid children's understanding of events, and they may be able to be involved in their parent's care, not be overburdened but to be helpful, and have the opportunity to be close and say goodbye. But in these circumstances children must also cope with the enormous problems of living with a chronically ill person. These may include long term family disruption, the progressive decline in their parent's health, continued uncertainty and a myriad of emotions. Watching a loved one die is a very difficult task. Children may feel great sadness and anxiety, but also reproach, anger and guilt when the family can no longer go out because their parent is too ill, friends cannot come round to play, their well parent is absorbed and exhausted from the care of the spouse and little attention is paid to their needs as children. With adequate support the family can help their children to adapt to the changes, and to express their feelings, which can be legitimized. Regular routines and open communication with children

can make the death more understandable and less frightening, with less chance of difficulties in the grieving process following their parent's death.

Unexpected / Sudden

Sudden deaths are believed to be more difficult to cope with than anticipated bereavements. They allow no time for anticipatory grief. The children's sense of security and control in the world may be shattered. The parent may have been present at the breakfast table as usual, but is never seen again. This type of death leaves the survivors with a sense of unreality about the loss - they can't believe that the person is dead, and may actively search for him. It also tends to provoke a lot of guilt, manifest in "If only...." statements, about things those left behind felt they ought to have done or said, but were never given the opportunity. Young children may be especially prone to guilt associated with their magical thinking. They may have harboured hostile feelings about the dead parent, even wishing them dead. In these circumstances they may attribute these thoughts with actual power and feel responsible for the occurrence. Sudden deaths are often characterised by traumatic aspects that parents wish to 'shield' the children from, and consequently they may lack the information they need to make sense of the loss. Another feature of this type of loss is the sense of helplessness and lack of perceived control. This maybe exhibited in children as a withdrawal from the outside world, or it may be mixed with anger that this should happen to their parent. The need

to blame someone maybe expressed in an increase in behaviour or conduct difficulties.

Suicide

Children who lose a parent through suicide are left not only with a sense of loss and unreality, but also a "legacy of shame, fear, rejection, anger and guilt." (Worden,1982). Of all of the feelings that suicide survivors experience, the ones that most strongly differentiate grief in these families is the sense of guilt and shame. Suicide carries its own stigma with it in our society (Osterweis et al, 1984), and the survivors are often treated differently than those of other bereavements. The children may not be told the true circumstances surrounding the death, or the family may 'pretend' that the death was an accident to avoid the stigma, deny the happenings to the children or tell them that what they saw was a dream. These 'family myths' (Cain, 1972) may be helpful in the short-term, but typically lead to difficulties in the grieving process, and additional difficulties of a lack of trust in the adult world. Usually the survivors, including children, experience guilt, feeling that they should have predicted and prevented the suicide in some way. This guilt may be exacerbated if there were interpersonal disputes in the family around the time of the death or if the children were unintentionally involved in the death in some way, by collecting the prescription for the tablets or by the parent having arranged for them to be elsewhere when the act took place. Children are often angry with their parent for abandoning them, and may turn this inwards, justifying it by

believing themselves to be to blame for being such unloveable, unworthy children. Their decrease in self-esteem combined with their guilt may encourage them to make retributions against themselves, or act out in order to make the world punish them. Finally the sense of helplessness and lack of control experienced by children following the suicide of one of their parents may make them fearful that the surviving parent may consider taking their own life too. The insecurity may cause the child to become clingy and more dependent on the remaining parent, or try to seek reassurances that this would not occur.

1.5.3 The role of Communication in the child's grieving process

Effective communication with bereaved children and openess between the surviving family members may be the key to ensuring adaptive grief, (Dyregrov, 1991). However, the surviving parent is often struggling to deal with the situation and his own emotions, and the children may be excluded in a misguided attempt to 'protect' them. This often extends to the few cultural rituals which exist to permit the bereaved to mourn, and therefore validate this. Silence deprives children of the opportunity to share their grief, and teaches them only that death is a 'taboo' subject.

Giving children information about their parent's death, in a manner in which they can understand it, can help them to adapt to the situation with a minimum of fear and confusion. It is important to know what a children understand, or what their own ideas of life and death are, as a starting point to discussion. Even young childrens' concepts of death and therefore their understanding of

the current situation can be enhanced by giving them information (Furman, 1974). Explanations based on plants and animals can demonstrate that death is a natural process, (Stickney, 1982). The death of a parent should be explained to children openly, directly and without euphemisms, such as 'Daddy's gone away', or 'gone to sleep'. These explanations fail to communicate the finality of death to children, and may cause fear, sleep disorders and further misunderstanding or promote the use of fantasy to fill in the missing details. Abstract explanations introducing Heaven and God are often siezed upon by carers in this situation, looking for a way of explaining death to children, but these tend to increase their sense of confusion unless religion has been a part of the their life before. Delay in giving children accurate information may reduce the trust they have in their remaining care-giver, and increase the likelihood that they will hear the news in an unplanned situation. In general, explanations will have to be repeated many times as the children struggle to take in the news, and gradually master the different aspects of the death. It is as though children have to build up a jigsaw of what has happened, and each time they manage to place a new piece they need to study it hard before moving on to find the next.

Often children and parents will hide their feelings from each other in order to protect the other party. This teaches only that feelings must be kept to oneself, and becomes a negative role-model for children. It also often removes their only outlet for talking about the situation. Language is the major form of communication in adults but children may well act out the events

and explore issues in play, or through drawings (Gumaer, 1984), and this should be acknowledged. Also, children are less tolerant than adults of strong feelings, they will often ask a few questions, and then want to go out to play. This reflects their less well developed coping strategies and shouldn't be interpreted that the child doesn't care.

The conclusions of studies that have looked at the outcome of children attending their parent's funeral are not consistent. Some researchers have stated that children who do not attend their parents funeral find it more difficult to accept the death (Bowlby, 1963; Furman, 1970). Others have reported that children may develop psychiatric symptoms of anxiety and phobias as a result of attending the funeral (Furman, 1976, 1974), although controlled studies showed that these symptoms were often present in grieving children independent of funeral attendance. Weller et al (1988) found that atypical reactions were associated with being forced to attend the funeral despite not wanting to go, that is, having a lack of choice or control, and the inadequate preparation of children prior to the funeral. Poor short term adjustment was no longer apparent at a two month follow-up. Literature (Dyregrov, 1992), about viewing the body and funeral attendance advocates that children should be involved if they wish, but that they must be well prepared for the experience. The surviving parent, or another trusted adult should tell them what will happen, or what the body will look like, how it is dressed and so on. The child should be able to reality test the body if they wish, by opening the eyes for example, as young children tend to do with sleeping adults, to

check that the dead person is not asleep. They may wish to look into the coffin, to check that the whole person is being buried, after all, we only bury bodies - What happens to the head? This experience, if done sensitively, can help children to be involved and to understand death, and gives them the opportunity to say goodbye. Funeral attendance has been correlated with a reduction in deviant behaviour and increased crying (Black et al, 1983).

1.5.4 The surviving parent and their effect on their children

Children's adjustment to the death of a parent is greatly influenced by the extent to which the surviving parent is able to continue to provide support, care and security for the children (Furman, 1974, Silverman and Worden, 1993). Open communication between the parent and child can facilitate the expression and understanding of emotions. But the parent may be so absorbed by grief that the child's needs go unmet, which may cause the child to deny the loss and suffer later emotional difficulties (Wolfenstein, 1966). Consistency and stability in the other areas of the child's life, such as home and school, help the child to retain some sense of control and security, as well as access to normal support systems. In the altered life circumstances, both economic and social, following parental death, changes may be necessary and these additional stressors may jeopardise the capacity of the remaining parent and child to cope with the loss.

1.5.5 Factors in the child

Age

There is no concensus about children of any specific age being at particular risk following a bereavement. Rutter (1966) found that later psychological disturbance was associated with loss at age 3-4 years. Birtchnell (1972) found a significant relationship with psychiatric disorder in adulthood only when the individual had been bereaved before the age of 10 years, whereas Hill (1969) found significant associations between adult depressive illness and bereavement between the ages of 10-14 years. In all of these studies there was a considerable delay between the death of a parent and the onset of psychological disturbance, making it less likely that the death itself was the sole factor leading to difficulties and/or referral. The inconsistency between the findings may be due to an oversimplification of outcome measures, such as the presence or absence of psychiatric symptoms or other problem behaviours, without considering intervening factors such as parental response to childrens' needs, support networks and subsequent life circumstances, such as poor parental remarriage (Berlinsky and Biller, 1982). In all of these studies the effect of a childhood bereavement is implicated retrospectively, and therefore no causal relationship can be demonstrated. These studies also used psychiatric populations and the findings may be specific to these groups.

Sex

The insufficient evidence available tentatively indicates that girls are more vulnerable to psychological disturbance following the loss

of a parent. The loss of a mother appears to be more significant for girls under 11 years (Brown et al, 1977; Birtchnell, 1971, 1972) and loss of a father for adolescent girls.

These differences may be due to the relative ease with which girls can acknowledge, express and discuss feelings in comparison with boys, (Dyregrov, 1988a). Girls' play tends to be more expressive and focus on human relationships, whereas boys, through social learning, are often taught to suppress feelings and look to the future. Whether by using denial males are more vulnerable to subsequent minor losses, or are more likely to develop somatic symptoms or physical health problems (Brown and Stoudemire, 1983) or problems in other areas of their lives, such as personal relationships, requires further study. The general assumption is that low initial levels of distress are indicative of a problem, such as absent or delayed grief. However, this may not signal pathology, but demonstrate coping strength and resilience, (Wortman and Silver, 1989).

Ordinal position

Birtchnell (1971) concluded from his study that the ordinal position of the child within the family affected the course of the child's grieving. Having an older sibling of the same sex as the dead parent seemed to protect against subsequent disorder, perhaps as the sibling assumed the role of the parent. However, being that elder sibling increased the risk of difficulties.

Personality and previous experience

Emotionally unstable children, and those who tend to be reclusive and isolated, will be more likely to experience

difficulties in their grieving, (Dyregrov, 1991), perhaps through their inability to mobilise adequate support systems through peers. From clinical experience, it is evident that childrens' capacity to face life crises can vary considerably. Previous experiences may have a differential affect on children's ability to cope with the loss of a parent. If the children have not been able to cope with painful losses or separations in the past, then they may be more vulnerable to emotional disturbance.

1.6 *Bereavement Services available to children*

Most professional interventions in the palliative stage of care, or post-bereavement, concentrate on the family unit as the 'patient'. As Furman (1974) states, communication within bereaved families is often severely disrupted, and family role relationships often become unbalanced (Hare-Mustin, 1979). The needs of children for continuing parental support to work through their grief validates working with the family, as it is unlikely that children can progress with the later tasks of grieving if their parent or caretakers are still working on earlier tasks in the process (Baker, 1992). However, a consistent finding in the literature on working with disaster survivors (Handford et al, 1986), children who have a terminally ill parent (Rosenheim et al, 1986) and bereaved children (van Eerdewegh et al, 1985; Blank,1975), is that parents tend to underestimate the extent and severity of their children's reactions compared to the children's self-perceptions of their coping. This denial by adults, and by society in general, of the effects of trauma and death on children creates a problem in providing treatment for children, as their gate-keepers need to be convinced of the usefulness and necessity of care before they can be accessed. Ethical problems abound, which have often been overcome by including the whole family in treatment. This reluctance to expose children to the arousal of painful grief is understandable, although in the long term it may be misguided.

Case studies of bereavement work with families have been reported in the literature (Hildebrand, 1989). These emphasise the

preventive nature of the work, ensuring that the family has accurate information about the bereavement, and promoting adaptive communication so that pathological coping strategies are not adopted by the family. Evaluating a family therapy model of intervention, Black et al (1983) showed that grief can be promoted in children and pathological outcomes reduced, in the short term at least, in comparison with no treatment controls. However, this study reported a 50% attrition rate, and the controls were not matched, as to contact them prior to the treatment, but not to offer them help, was deemed to be unethical.

Blank (1975) comments on the Crisis Consultation bereavement service which has been established since 1960, with the philosophy that seeing bereaved families immediately after the death of a significant family member for a short period, can prevent the establishment of maladaptive coping and emotional difficulties. This service did not advocate pathologizing grief in any way, but sought "to reach those who in the ordinary way would not have needed psychiatric help." It focused on normalizing their grief reactions, some of which, in other circumstances, may have been viewed as departures from normal mental health. Unfortunately the service has not been formally evaluated, but Blank (1975, p.185) makes the observation, " Our experiences with children who come many years after the crisis confirm that their treatment usually takes much longer than that of children brought early and that some of those who are so defended or set in their behaviour pattern by the time they reach us that treatment is only partially successful.".

Siegel et al (1990) also advocate 'time-limited interventions'

with all bereaved children. Their work focuses on helping families where one of the parents is terminally ill. Despite having an 'advantage' in that the death of the parent can be anticipated and somewhat prepared for, the service remains involved with the families for up to six months post-death in order to promote 'healthy' grieving. Their intervention focuses on individual work, supporting well parents in dealing with their own grief and therefore supporting continuance of their parental functioning. This has advantages in that grief is not a discrete event but rather a life transition which requires children to master the changing consequences of the loss throughout their development (Worden, 1991). Preparing the parent for that process enables the children to be continually supported. However, evidence that parents underestimate their children's grief reactions, and the lack of influence over the involvement of children in communication and burial rituals when the death is not anticipated and services are not involved, may make working solely with parents following unexpected deaths less effective.

When considering treatment for children, groupwork with children of divorced parents has been shown to be an effective therapeutic intervention (Gwynn and Brantley, 1987). Children are already familiar with group experiences through school, and working in this way is an efficient use of a skilled therapist. However it must be recognised that groupwork can never be the treatment of choice for all children. It can provide the setting in which to conduct some psycho-educational work with children and to help them to accept the reality of the loss and the reality of death;

the first task of grieving (Baker, 1992; Worden, 1982; Furman, 1974). Groupwork also provides the opportunity to normalize the circumstances and feelings of the children, as bereaved individuals often feel different from the other children in their school, as they believe that they alone have suffered the loss of a parent through death. In this way the group members can offer each other support, and share their experiences and feelings and begin to rebuild their self-esteem. Groupwork involving adults in both formal and informal meetings, has been found to be successful in achieving these functions (Leich and Davidson-Nielson, 1991). Groupwork also lends itself to certain types of intervention, such as 'collective therapeutic rituals' (Rando, 1985). These ceremonies may be particularly valuable for children, who are often excluded from the rituals advocated by society which legitimize the expression of feelings and memories of the deceased. Groupwork could also be used, as part of a wider service, to provide initial input to, and contact with, all bereaved children, with those deemed to require further help being passed on for more individualised therapy.

The effectiveness of an intervention with bereaved individuals is difficult to demonstrate conclusively as adjustment depends on many intervening factors. The literature has focused primarily on case studies of individual treatment (DeMuthberg, 1973; Greenberg, 1975). Models for groupwork with bereaved children have been proposed (Masterman and Reams, 1988), but only one outcome study of a children's bereavement group has been undertaken (Pennels and Smith, 1992). In this study 5 bereaved adolescents who had been

referred for bereavement counselling took part in a support group over a 12 week period. Self-evaluation questionnaires, asking about the respondent's behaviour, were administered at the beginning and end of the group, and again at six months follow-up. Data was presented on 4 participants. No differences were found between the pre- and post group scores, although the study reported a significant reduction in depression, somatization and isolation and increased functioning at school at the six month data collection point. However, despite showing beneficial outcomes, this study was methodologically flawed. The lack of a control or a comparison group means that the differences found cannot be assumed to be due to the groupwork intervention, they may be attributable to other intervening variables, such as time. The measure used was not accompanied by any reliability or validity data, and its construction and consistent phrasing encouraged the use of a response bias. Qualitative data did support the positive outcome, and indicated that the participants valued the opportunity to talk openly and share their experiences and thus lessen their sense of isolation. The fact that this group was established as a response to referrals of children who were not coping well with the death of their parent indicates that they probably differed from other bereaved children initially, although no quantative data is available to confirm or quantify this. The group functioned as more of a crisis intervention rather than a preventive service that would be available to any bereaved child.

As far as the author is aware, there has been no study to

date of an unselected sample of recently bereaved children receiving treatment and comparing them to untreated controls.

1.7 Methodological difficulties

Studying children's understanding of death has several methodological difficulties, not least of which is that the information has to be accessed from the children, and it may therefore be limited by their verbal skills. Spinetta(1974) demonstrated the fallacy of equating the child's inability to verbalize with a lack of knowledge about death, and perhaps this danger extends to the whole of the study of grief. The limited work available for review in the bereavement field is based on cross-sectional data collections, or single case study designs, from which longitudinal inferences are drawn. The studies have generally utilized different measures, which have few, if any, validity or reliability checks, or have relied on qualitative evidence. The lack of no-treatment bereaved control groups means that different subject characteristics, cohort effects and the simple passage of time may be responsible for more of the improvement in the participants than the success of any intervention. Other potential variables which may contribute to individual differences within studies or to contradictory findings between studies are the social class, experience with death, media influences and religiousity of subjects, in addition to differing therapist characteristics, all of which are almost impossible to disentangle. Consequently caution must be taken in drawing conclusions from the studies. The ethical issues surrounding the study of bereavement, and the sheer number of possible intervening variables which may influence the grieving process, make 'true'

experimental research difficult to undertake.

Several studies have described the experiences and reactions of children following the death of a loved one (Elizur and Kaffman, 1982, 1983; Raphael, 1983; Silverman and Worden, 1993). But, as far as the author is aware, no studies to date have attempted to evaluate the efficacy of conducting grief work with bereaved children and including a no-treatment bereaved control group, or a matched non-bereaved comparison group of children in the research.

Chapter 2

The Present Study

Following the Pennels and Smith (1992) study, which indicated that groupwork with bereaved children may be an effective intervention strategy, as well as being economical in terms of therapeutic time, this study aimed to more thoroughly evaluate this type of intervention. In this study bereaved children were offered the opportunity of participating in a psycho-educational group. Some of the children who were put forward for assessment and possible inclusion into the group had already received an intervention related to their bereavement, so this variable was controlled for in the design of the research. Due to the lack of resources, no future groups or interventions for bereaved children could be guaranteed at the outset of the research, and therefore it was felt that it would be unethical to include a no treatment bereaved control group. In the event, only a small number of bereaved children were available for inclusion in the study, and so a comparison group of non-bereaved children was included, matched to the bereaved group in terms of their age and sex.The small number of cases available for this intensive design makes this an exploratory pilot study of the effectiveness of groupwork with children who have lost a parent in terms of their behavioural and cognitive development.

2.1 Aims

1) To devise a pilot programme aimed at meeting the needs of bereaved children.

2) To establish an effective evaluation package for bereavement interventions with children.

3) To evaluate the effectiveness of groupwork as an intervention for children who have lost a parent through death.

4) To make recommendations for future service development in this field.

2.2 Hypotheses

1) Children who have not been bereaved will show fewer psychological symptoms than the bereaved children, as measured by the Behaviour Rating Form.

2) Those bereaved children who have already received an intervention will initially show a better adjustment to bereavement than children who have been bereaved but have not been involved in individual grief work, as shown by a higher score on the Behaviour Rating Form (see Appendix D) and the Mourning Bridge (see Appendix F).

3) Attending a bereavement group will enable children to cope better with the loss of a parent, as show by an increased score on the Behaviour Rating Scale following the intervention.

4) Children who have been bereaved and are therefore experienced

with death, will have a more complete understanding of the concept of death and grieving than the comparison 'unexperienced' children, as measured by the Comprehension of Death Questionnaire (see Appendix E).

5) The surviving parent's adjustment to bereavement will be correlated with their child's level of adjustment as measured by the Mourning Bridge.

Chapter 3

Method

A research proposal was submitted to the Gloucestershire District Ethical Committee, and was approved.

3.1 Participants

3.1.1 *Selection of the sample*

Due to the nature of the intervention, and the study, the sample was essentially self-selected.

Children were considered for inclusion in the bereavement group if they had lost a parent through death, and they were between 8-12 years old. Originally a time period criteria of the bereavement having occurred within the last year was proposed. But the small number of subjects available necessitated the retraction of this requirement. This is in accordance with Rutter's (1966) finding that children are often referred for help with bereavement related difficulties an average of 4-5 years after the loss.

Families in which one parent had died, leaving dependent children of a suitable age for inclusion in the group, were originally to be identified and followed up via the death records at the District General Hospital. However, despite the approval of the Ethical Committee, access to the Medical Records Department was denied. In view of this difficulty in locating appropriate participants, the Oncology and Accident and Emergency Departments were approached directly by the

researcher, and expressed their willingness to inform her of any instances where children within the required age range may be bereaved of a parent. Local G.P. surgeries were informed about the proposed Bereavement Group and its aims by letter, (see Appendix A), and were asked to forward the information to any patients attached to their practice who may benefit from such a service. Health Visitors, the Hospital Social Services Department and the local branch of the bereavement counselling service CRUSE were also informed of the initiative.

3.1.2 *Engaging the Participants*

Those families who expressed an interest in the Bereavement Group, or were referred by other professionals, were contacted by the researcher and a domiciliary visit was arranged. At the meeting with the family more information about the intervention was provided and their consent to participate in the study was sought, (see Appendix B). The initial assessment was conducted, in which all of the measures were administered. These provided background information about the child's family, the 'story' of the death and any subsequent changes in the circumstances of the family since the bereavement. A behaviour profile of the child was completed by both the parent and the child, and they were both asked to rate their current position in the grieving process. In addition to giving the families information about the bereavement intervention, with the consent of the parent

and child, this visit also served as the 'pre-intervention' data collection session. The children and parents were sent a written invitation, and practical details of the intervention respectively, a week before the groupwork (see Appendix A).

3.1.3 *Characteristics of the sample*

14 children were referred to the Bereavement group :

6 by the Palliative Care Team (PCT)

5 via G.P. surgeries

2 via CRUSE

1 by his school teacher

One boy was excluded from the study. He had lost his Father and 2 brothers through suicide, and his closest aunt had died in the two weeks prior to the group. It was felt that the multiple nature of the bereavements and their recent nature made his inclusion in the group inappropriate. The remaining 13 referrals were divided into two groups on the basis of whether or not the child had received a previous intervention from the services. If children had been seen, either prior to the parent's death, or for bereavement work, they were assigned to Group A. If the children had not previously received any services they were assigned to Group B.

Group A

Six of the children who were referred had received a previous intervention from the PCT. Three of these children had lost a

parent by sudden (unexpected) death and three by expected death, although in one case the Father's illness was only diagnosed as being terminal 2 weeks before his death. This group of children was made up of 3 girls and 3 boys, whose mean age was 9½ years, with the range of ages being 8-13 years. The older child had been included as she was the elder sibling of one of the other children. The time which had elapsed since the death of the parent varied from 6 months to 2 years, with a mean of 1 year and 4 months. In half of the cases the children had been bereaved of their mothers.

A couple of vignettes of the children included in this group are presented;

Case 1 A young boy aged 8 whose mother had died suddenly as a result of a cerebral heamorrage one year ago. The boy had been trapped in the same room as his mother, who was 'stuck' in a prostrate pose, for some hours before they were found by the family. His older brother had become very depressed and had left home. His father also sought help for depression, was unemployed and very isolated. The child had difficulties in concentrating at school, would often cry and found interacting very difficult. He reported having vivid dreams and would often fantasize. He had previously had 4 individual sessions with a psychologist.

Case 2 A 9 year old boy whose Father had died a year ago in Intensive Care following an 8 week pneumonia virus. His behaviour had worsened considerably during his Father's

illness, and he continued to be aggressive but clingy after his death. He saw a psychologist for 2 sessions with his Mother, but would not talk about his Father with her.

Group B

Seven of the children who were referred had not received a previous intervention. Six of these had lost their parent by unexpected death, and one through expected death. In this group all of the children had been bereaved of their fathers. This group was made up of 2 girls and 5 boys, whose mean age was just over 9 years, with the range of ages being from 8-12 years. The time since the death of the parent varied from 1 year to 1½ years, with a mean value of just over a year. Again two examples of cases are presented.

Case 1 Two boys aged 8 and 10 years whose Father committed suicide a year ago by carbon monoxide poisoning. The family home was repossessed following the death. The boys were teased at the Catholic school they attended. In the suicide note, the oldest boy was given the task of looking after the rabbit. The pet was subsequently lost during the move. He became withdrawn and very protective of his Mother and younger brother. The younger boy had slight learning difficulties, and he withdrew into fantasy. He became very aggressive, his asthma attacks increased markedly and he started to have difficulties with nocturnal enuresis.

Case 2 Two boys aged 8 and 12 whose Father had died suddenly from a brain tumour a year ago. He was on a life support machine for 5 days, although the youngest boy was not allowed to visit him. The parents had just bought a new business together, which the Mother had to sell. The youngest boy was very angry and aggressive, but clingy with his Mother. The older boy frequently had nightmares and was sleeping with his Mother. He also visualised his Father's presence around the home and had become more withdrawn.

2.1.4 *Comparison Group*

Due to the lack of any guarantee of future specialist interventions for bereaved children, it was deemed unethical to allocate participants to a no-treatment bereaved control group. Also, if bereaved children and their parents refused to participate in the intervention, but were willing to complete the measures, it was felt that these individuals may represent a biased sample where parents either did not recognise the needs of their children, or where the children were coping adequately with the loss and were deemed not to require further help. In the event, not enough children were referred to have made a control group a viable option, and all of the families contacted were keen to participate in the intervention. Therefore, a comparison group of children who were inexperienced with death and matched for age and sex in a pairwise fashion to the 13 children included in the two

treatment groups, was obtained from a local primary school. The children were picked randomly from the register conforming to the sex and age group of each bereaved child. Comparison children for the two participants attending secondary school were obtained from the children of friends who were not involved in any way,in the study or clinical work.

3.2 Design

The quasi-experimental design utilized in this study is a repeated measures pre and post intervention, between group design, (see table 1). This design allows for comparison between the bereaved and comparison individuals prior to and after the group work. In addition to this, the design also enables within group differences between group A and group B, that is, bereaved participants who had received a intervention before the group work and bereaved individuals who had not received any professional help, to be analysed at the various data collection stages. The 4 month follow-up data point assesses whether any post-intervention differences are maintained over time.

TIME OF ASSESSMENT	BEREAVED GROUP (N = 12)		CONTROL GROUP (N = 12)
PRE	A	B	C
Intervention	YES	YES	NO
Post (6 weeks)	A	B	C
Follow - up (4 months)	A	B	C

Table 1 An illustration of the design of the study

3.3 Measures

3.3.1 *Parental Interview* (see Appendix C)

This is a structured interview designed to obtain the relevant background information about the parental death, the family structure, support systems, participant characteristics and other concurrent life events, necessary prior to accommodating the child within the Bereavement Group. It provided a wealth of qualitative information, although its primary purpose was not as a research instrument but as a clinical tool.

Administration

The interview was completed at the initial interview with the family, and on subsequent occasions the parent was asked if any of their circumstances had changed, in order to update the information, although the interview was not formally undertaken again as this would have involved much unnecessary repetition.

3.3.2 *Behaviour Rating Form* (see Appendix D)

This questionnaire was adapted from the study of Pennels and Smith (in press, 1992). The content of this self-rating form covers 5 behaviour categories, with 6 questions in each, resulting in a total of 30 questions. The categories covered are anger, anxiety, school work, somatization and isolation. Each respondent was required to rate his/her own behaviour over the last couple of weeks on the 4 point Likert type

ranging from 'ALMOST ALWAYS' to 'ALMOST NEVER'. An even number of categories was deliberately chosen to force the respondents to decide the direction of their behaviour. To conform to the usual convention of a scale containing an equal number of positively and negatively phrased items (Moser and Kalton, 1979), and to minimise the effects of a response set, half of the statements from the original form were re-written.

Scoring (see Appendix D for scoring key)

Each response was scored from 1-4, with a high score representing good adjustment with respect to that behaviour category. The possible scores on the questionnaire range from a minimum of 30 to a maximum of 120.

Administration

This self-rating form was completed by the children and surviving parents prior to the intervention and at the post-intervention and 4 month follow-up data collection points.

Reliability

A sample of 10 non-bereaved primary school children, who were not involved in the study, completed the Behaviour Rating Form on two occasions(). The data obtained was analysed using the computerised SPSS/PC package, in order to calculate the reliability coefficients for the measure.

Guttman Split-half coefficient = .9343

Cronbach's Alpha for part 1 = .7481

Cronbach's Alpha for part 2 = .6737

Test - retest correlation = .7524

The Rating form shows good internal consistency, and with 5 component behaviour categories, the internal homogeneity would not be expected to be significant. Ideally a factor analysis would show five clusters representing these different categories, although the data available was insufficient to perform such a calculation.

The test- retest reliability, conducted on 10 non-bereaved individuals over a six week period, demonstrated the consistency of the Rating form over time. Therefore, any significant changes in scores on this Rating Scale are likely to represent real changes in behaviour.

Validity

The Rating Form is based on a previous measure, and has face validity in that it includes the behavioural effects of a bereavement on children as described in the available literature (Dyregrov, 1991). Also 8 professionals, who had worked in this field, were asked to generate all of the behavioural consequences that they could think of, of a parental bereavement on children. Fifty behaviours were generated, all of which had been covered in the statements on the behaviour Rating Form.

3.3.3 *Comprehension of Death Questionnaire* (see Appendix E)

This questionnaire was developed specifically for use in this study. It was based on the components of the concept of death as described by Kane (1979), which are listed below.

1) Realization - An awareness of death, of being deceased, or an event which happens which makes the living die.

2) Separation - An awareness that the dead are no longer present in the living world.

3) Immobility - Awareness that the dead are completely inactive and cannot move.

4) Irrevocability - Awareness of death as being a permanent and irreversible state.

5) Causality - Awareness that death can be caused by internal and external agents, or a combination of the two.

6) Dysfunctionality - Awareness that the dead person's physiological bodily functions are no longer working.

7) Universality - Awareness that everybody dies.

8) Insensitivity - An awareness that the mental processes of the dead have ceased, so that they no longer think, feel or dream.

As well as asking questions about the childrens' level of understanding of death, the questionnaire asked about their understanding of the rituals surrounding death, and about the childrens' perceptions of their own mortality.

Scoring

A child's ideas about death were referred to as components, which could be absent or present.

A component was defined as being completely present if "notions like those of an adult" were held, or absent if they were "indefinite, inconsistent or unlike those of an adult", as in Kane's (1979) original research.

The expected age of mortality was recorded as a point on the natural 'age' interval scale, and the comments about rituals were recorded as qualitative data.

Administration

The questionnaire was administered as a structured interview, which was taped and then transcribed to facilitate the naturalness of the conversation. This was administered prior to the intervention, and at the post intervention and follow-up data collection points.

Pilot study

Ten children who were inexperienced with death were tested using the proposed format for administration of the questionnaire, half by their school teacher, and half by the researcher. There was no difference in the quality of the responses between interviewers, showing that the familiarity of the interviewer was not a factor in the replies given, and the comments of the respondents demonstrated that the procedure was not stressful to complete.

2.3.4 *Mourning Bridge* (see Appendix F)

There were two forms of this scale, each included the same task, but the wording of the instructions varied between the adult and the child form.

This is a hypothetical visual analogue scale (Aitken, 1969) based on a clinical tool used by Huber and Gibson (1990),to self-assess the respondent's adjustment to their bereavement. The aim of this measure was to calculate the correlation between the parent and child's subjective sense of their own grieving process.

Administration

The Mourning Bridge was administered to both the parent and child at the initial interview and at the post-intervention and follow-up data collection points. The instructions (see Appendix F) were read out, whilst pointing to the relevant parts of the bridge.

Scoring

The top of the bridge is of fixed length (250mm). The difference between the respondents 2 marks are deemed to represent the distance they have travelled along the 'bereavement journey', and the length between the two marks represents their score.

The differences between the respondent's scores at the different stages, that is the change in their perception of their grieving process over the duration of the study, were also calculated.

3.3.5 *Satisfaction Questionnaire* (see Appendix G)

There were two forms of this questionnaire, one for the parents, to record any changes in the behaviour of their child/ren and if they had been satisfied with the procedures used to engage them in the Bereavement Group programme. The children's form asked whether the children felt that the Groupwork had been useful, which parts they had particularly enjoyed or not enjoyed and what, if anything, they had learned..

Administration

The adult form of the Satisfaction questionnaire was sent to the parents one week after the completion of the Groupwork, with a SAE enclosed for their anonymous reply.

The children's form was completed at the end of the Groupwork, again anonymously, and handed into the researcher.

Scoring

This Form provided qualitative data about the content of the group work. The information was not in a format which could be numerically scored. However, the comments from both forms were collated and could be used to guage the most successful activities, and to modify future programmes.

3.4 Procedure

A draft programme was compiled, discussed and adapted by the researcher and the co-therapists; a Clinical Psychologist, Paediatric Social Worker, Teacher and a Trainee Clinical Psychologist, at a series of planning meetings.

An outline of the Groupwork.

(N.B. Please refer to Appendix H for details of the full intervention package).

DAY 1

TIME	ACTIVITY
9.00	Registration - badge-giving, identifying child and loss - Meet with small group leaders - individual and group photographs taken - children put their photographs of the special person who has died, up in the gallery.
9.30	Welcome - Introduction and group 'rules' Group leaders introduce themselves Some general points about grief.
10.00	Story - "Saying Goodbye to Daddy" Vigna,J
10.20	Everyone is invited to say who they are, and the person who has died.
10.40	Mid-morning snack and drink

11.00 Game - A floor-size version of "All about me" developed by Peta Hemmings, 1991, played in three teams.

12.00 - 1.00 - Lunch, served in the hospital canteen, followed by free play.

1.00 Energizer - Activity involving running to different walls of the room to denote 'yes' and 'no' responses to questions.

1.30 Feelings - Demonstration, using water, containers and cling film, of how we bottle up feelings, and therefore block them from being resolved, and prevent positive feelings from entering.

2.30 Drink break

2.45 SMALL GROUP WORK - To focus on issues to do with their 'story' of what happened.

3.30 STORY - 'The Original Warm Fuzzy Tale' (Steiner, 1988)

Energizer- 'Warm fuzzies', i.e. pom pom necklaces were hung in the garden, and the children had to retrieve these and 'give' them to someone else.

4.00 CANDLE-LIGHT CEREMONY

- Everyone sits in a circle, and the ceremony explained. Each child to light their candle and say, " This candle represents 'X'....and the thing I remember about 'X' is....."

5.00 Story - "Badger's parting gifts" Varley, S (1984)

5.30 Parents arrive: Goodbyes.

DAY 2

TIME ACTIVITY

9.00 Welcome - "world greetings" - different ways of saying hello.

9.30 MEDICAL SESSION

- How can we tell when someone is dead? Body parts quiz. Nurses available to demonstrate taking blood pressure and pulse.

10.00 DOCTOR - Questions from post-box for doctor.

10.45 Mid morning snack and drinks.

11.00 SMALL GROUP WORK

- Focusing on the future, life without 'X'. Craft material available.

12.00 Lunch, followed by team game of kick rounders

1.30 'Winston's Wishes message to be completed.

- All of the children write a message to each other, which are then given, and used to decorate their gold cardboard balloons.

2.00 (One facilitator left to meet parents for brief session) to convey what has been covered during the group)

- Children decorate hyacinth pot, which has the bulbs prepared inside.
- Write messages for balloons
  One message for 'X', and one for the future.
- Satisfaction questionnaires completed

3.00 Going Home Bags - contents explained

- Teddy
- Their 'Winston Wish message balloon
- Rock, smooth stone and gem stone
- Names and addresses of other children

3.30 Parents join the children

- the parents also write messages to 'X' and the parents and children invited to share their messages before attaching them to a family balloon (helium filled).

4.00 BALLOON CEREMONY

- Children, parents and leaders make way to balloon release site.
- Song, "We are still a family"
- Balloon release.

GOODBYES.

CHRISTMAS CEREMONY

TIME	ACTIVITY
5.00	Welcome
5.05	Story - "Winston's Christmas Story", Crossley, D (in press).
5.20	Candle ceremony
5.50	Music- "We Remember" to the tune of KUMBA YAH - Silent Night - Twelve Days of Christmas, with actions
6.05	Food and drinks
6.20	"Warm fuzzies" and closure - each child received a Winston Christmas card with a special message inside.

3.5 Analysis

Although some of the children were from the same family, they were treated as individuals in the analysis. The observations may not be totally independent, but recent research suggests that a wide variance of attitudes and behaviour exist in children raised in the same family (Dunn and Plomin, 1990).

Rating scales, such as the Behaviour Rating Form, provide an ordinal level of measurement, but the data are often treated as interval data as equal scores from the same individual reflect equal levels of that behaviour occurring (Diekhoff, 1992).

The quantative data was analysed using the computerised statistical package SPSS PC. The Multivariate Analysis of Variance (MANOVA) procedure was used to compare differences between and within Groups A,B and C.

Correlational statistics were used to assess the relationship between parental and child data on the Mourning Bridge measure. Content analysis techniques were applied to the qualiatative data gleaned from the Comprehension of Death Questionnaire. The other descriptive data was collated.

Chapter 4

Results

One participant in the Bereavement Group, who had not had any previous help, did not attend the second day of the intervention. The data for this child, and the comparison child matched to him, were not included in the analysis.

4.1 Behaviour Rating Form

4.1.1 Differences between the bereaved and the comparison groups

The children's self-report ratings of their behaviour were analysed using a 2-way split plot analysis of variance (ANOVA), with groups (2 levels) and time (3 levels) as factors, via the MANOVA procedure on SPSS/PC.

The Box's M multivariate test of homogeneity was not significant on any of the analyses, demonstrating that the variances of the ratings, across the bereaved and control children and over the three data collection points do not differ significantly. Therefore this assumption of the F ratio statistic is fulfilled.

The initial analysis, looking at differences between the bereaved and control children over time (see Figure 1), revealed a significant effect of the Group variable, that is a significant difference between the bereaved and the control groups of children.

$F\ (1,21) = 10.42,\ p<.004$

From visual inspection of the data it is apparent that the bereaved

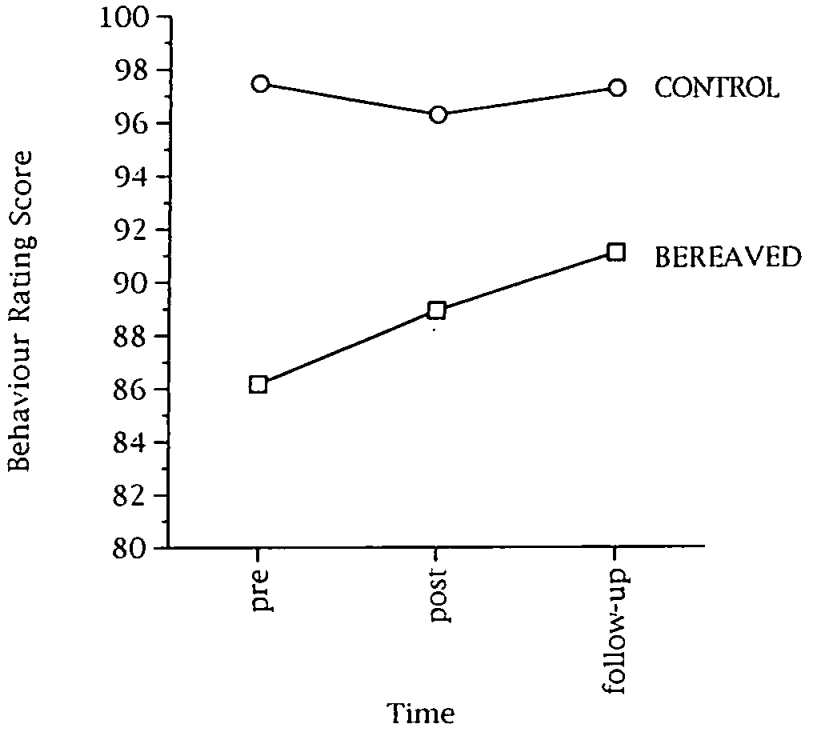


Figure 1. The mean scores from the Behaviour Rating Form of the bereaved and control children over time.

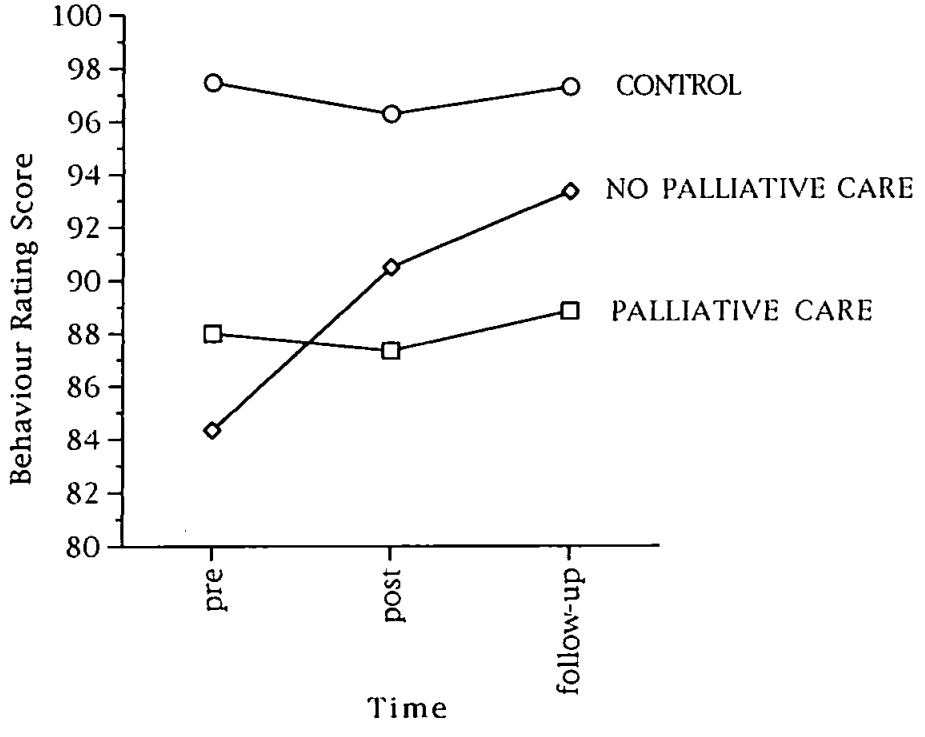


Figure 2. The mean scores from the Behaviour Rating Form for the control group, the bereaved children who had previously received professional help, and those who had not, over time.

children scored significantly less on the Behaviour Rating Form than the non-bereaved participants.

The analysis showed no significant difference in the behaviour rating scores over time;

$F\ (2,42) = 1.2,\ p<.313$

or any interaction between the group variable and time;

$F\ (2,42) = 1.47,\ p<.242$

As a significant effect of the group variable was found, as predicted, unrelated t-tests were used to explore where this difference lies. (see Table 2).

	Control	Bereaved	t value
PRE mean	97.45	86.17	5.05**
SD	7.27	10.02	
POST mean	96.27	88.9	3.03*
SD	6.99	6.93	
F-U mean	97.27	91.08	2.1
SD	6.56	6.54	

Table 2. The means, Standard deviations (SD) and t values of the Behaviour Rating Scores, for the bereaved and control children at the three data collection points. (* = p<.01; ** = p<.001)

4.1.2 Differences within the bereaved group

The data of the bereaved participants were then analysed separately for those children who had previously received some professional help and those who had not. The mean scores are diagrammatically represented on Figure 2.

Having found significant differences between the behaviour scores of the bereaved and comparison children at the pre- and post data collection points, comparisons with the control group, using unrelated t-tests, were made separately for bereaved children who had received some professional help prior to the groupwork (pc) and for those who had not (no pc).

	Control	pc	t value	Control	no pc	t value
PRE mean	98.5	88	2.6*	96.3	84.3	5.2**
SD	7.27	10.4		7.27	10.2	
POST mean	97.6	87.3	2.5	95.1	90.5	1.87
SD	6.99	7.5		6.99	6.59	

Table 3. The means, Standard deviations (SD) and t values of the behaviour rating scores for those children who had previously received help (pc) and those who had not (no pc) over time.
(* = $p<.05$; ** = $p<.01$)

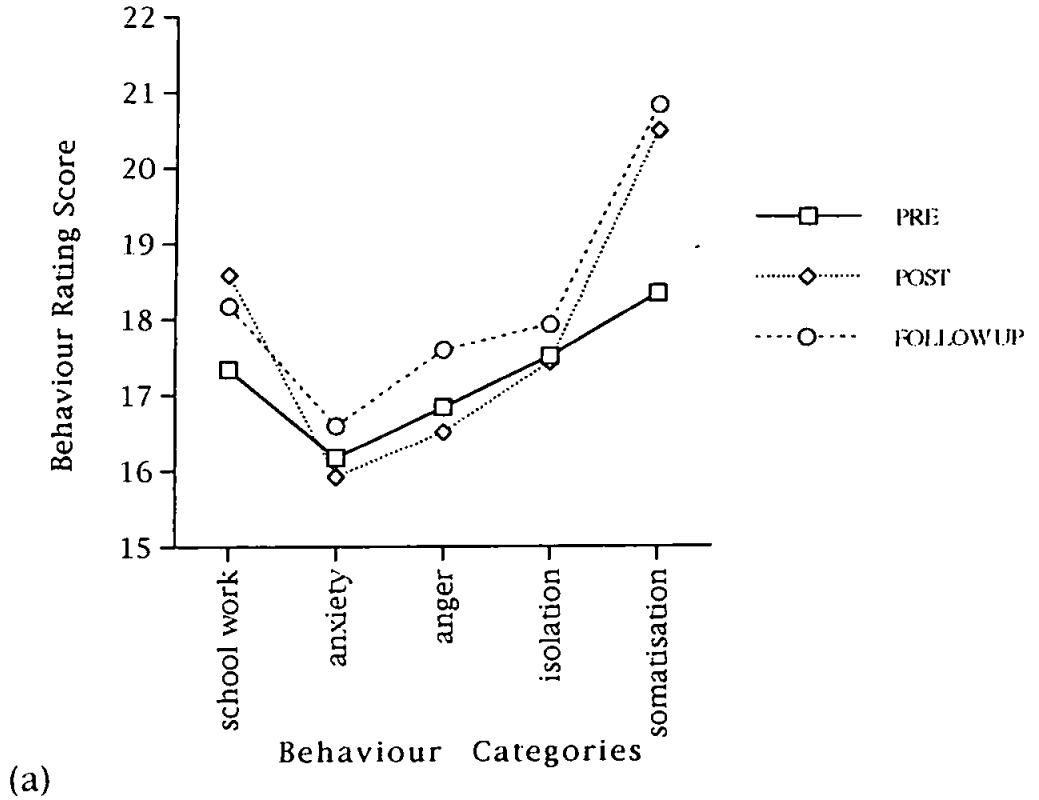
4.1.3 Differences in scores on the sub-tests

The scores for the separate sub-tests of the Behaviour Rating Form were analysed using a 3-way split plot Anova, with groups (2 levels), subtests (5 levels) and time (3 levels) as factors.

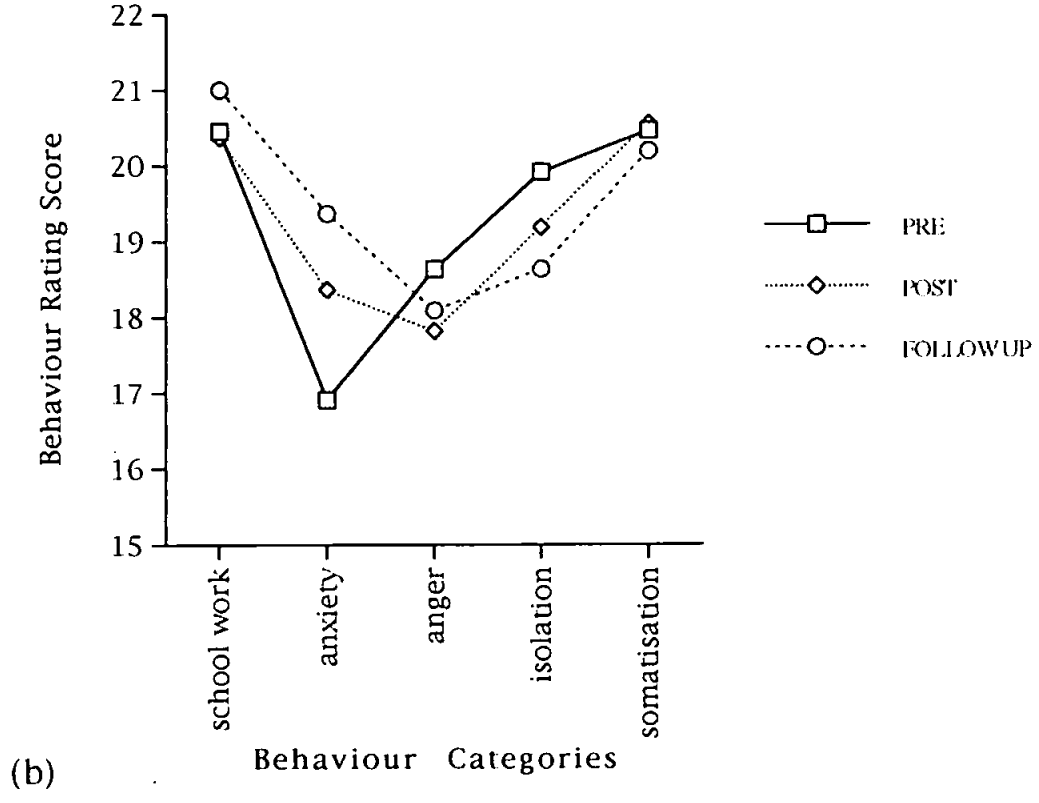
There was a significant effect of the group factor, showing that the scores of the bereaved and comparison groups of children on the subtests were significantly different from each other.

$F(1,21) = 9.07, p<.007$

The mean scores of both groups over time are illustrated in Figures 3a and 3b respectively.



(a)



(b)

Figure 3. The mean scores of a) the bereaved and b) the control children on the subtests of the behaviour rating form.

There were no significant differences in either of the groups scores over time, showing that the scores did not vary significantly over the three data collection points.

$F\ (2,42) = 0.98,\ p<.38$

Also there was no significant interaction between the subtest, group variable and time;

$F\ (8,168) = 1.93,\ p< .058$

This borderline score is possibly due to chance effects operating over the large number of analyses carried out.

4.1.4 Differences between the parent and child ratings

The bereaved children's self ratings of their behaviour were then compared to their parent's ratings to see if the two data collection methods resulted in significantly different data. A 2-way split plot Anova, with group (2 levels) and time (3 levels) as factors, was performed on the parent and child data Data was only available from 7 parent-child dyads due to the exclusion of parental scores as a consequence of missing data.

The analysis showed that there was no significant difference between the child's self ratings and their parent's ratings of their behaviour;

$F\ (1,6) = .04,\ p<.847$

And no effect of time;

$F\ (2,12) = .6,\ p<.564$

There was also no evidence of an interaction between the different raters and time;

$F\ (2,12) = .34,\ p< .716$

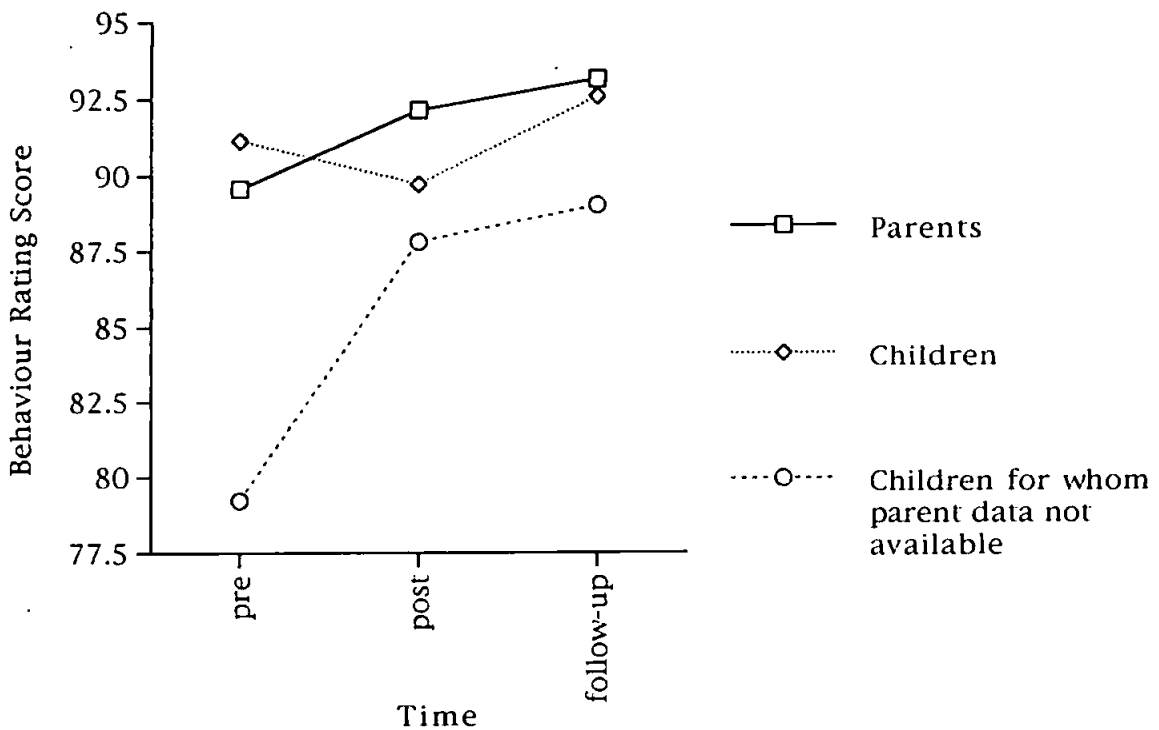


Figure 4. The mean scores from the behaviour rating form comparing the bereaved childrens' self ratings and their parents' ratings of their behaviour. The ratings of the bereaved children for whom parental data was incomplete are also shown.

The mean scores obtained from the children's self-ratings and the parental ratings are illustrated in Figure 4. This Figure also shows the parental data with the missing values calculated pro-rata, and shows that the children for whom data was incomplete, were those who were not functioning as well behaviourally as the other bereaved children.

4.2 The Comprehension of Death Questionnaire

4.2.1 Acquisition of components of the concept of death

The children's understanding of the concept of death was almost complete prior to the intervention, independent of whether they were bereaved and therefore experienced with death, or whether the were in the comparison group and had no immediate experience of death. Figure 5 illustrates the children's knowledge of the various components of the concept at the pre-intervention data collection stage. Although some children's understanding of the concept improved slightly, this increase occurred in both bereaved and control groups, and was minimal as the ceiling level had been achieved already in several of the components.

The results seem to indicate a developmental trend, with knowledge increasing as a function of age rather than experience (see Table 4).

Components	8 years n = 10	9/10 years n = 8	11/13 years n = 6
Realization	100	100	100
Separation	100	100	100
Immobility	100	100	100
Irreversibility	40	100	100
Causality	80	100	100
Universality	90	100	100
Dysfunctionaliy	40	75 (n=6)	66 (n=4)
Insensitivity	50	38 (n=3)	100

Table 4. Percentage of age groups of the whole sample who have fully acquired the component.

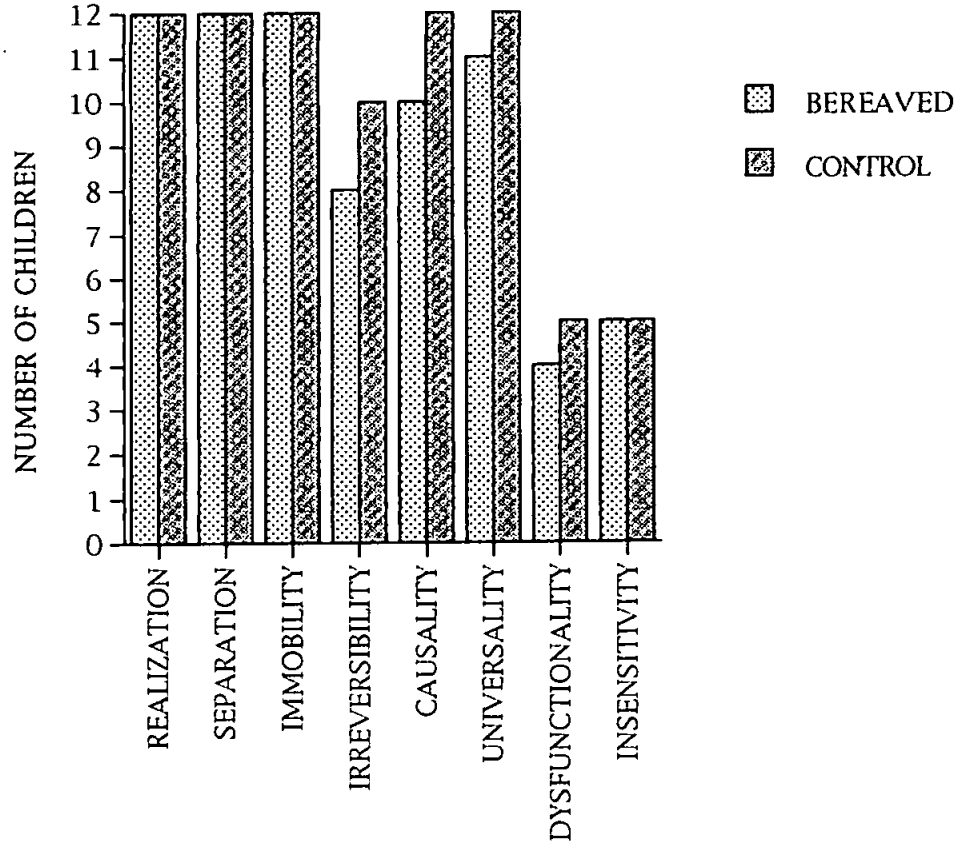


Figure 5. The bereaved and control childrens' knowledge of the components of the concept of death prior to the group work intervention

However, analysis using the Page's L Trend test is not significant;

$L = 102.5;\ p<.05$

4.2.2 Predicted life span

One of the questions on the questionnaire was, "At what age do you think you will die?" The interval data collected from this question was analysed using a 2-way split plot analysis of variance (ANOVA) with group (2 levels) and time (3 levels) as factors.

There was no significant difference between the expected life span of the bereaved and control children;

$F\ (1,17) = 1.1,\ p<.31$

However, in spite of the lack of statistical significance, the two groups did differ markedly in their responses, with the bereaved children tending to give a much lower age than the control children (see Table 5). The small sample sizes and large variances probably prevented this from producing a significant effect.

	Bereaved	Control
PRE mean	68 yrs	79 yrs
SD	19.03	11.16
POST mean	81.5 yrs	84 yrs
SD	12.47	10.3
F-U mean	84.2 yrs	84.7 yrs
SD	8.8	7.3

Table 5. Mean values and standard deviations (SD) of the children's perceived age of death.

However, there was a difference in the predicted ages given at the 3 data collection points, that is the ages given varied

significantly over time.

$F\ (2,34) = 6.19,\ p<.005$

The predicted ages of death for the whole sample were further analysed using a related t-test to see where this difference was located.

The t value for the difference in ages given before and after the group was $t(20) = 2.5,\ p<.05$

The t value for the difference in ages given post-intervention and at follow up was $t(20) = .8$ which was not significant. Therefore all of the children's predicted life spans increased over the duration of the intervention

There was no interaction between the two groups of children and time;

$F\ (2,34) = .82,\ p<.451$

4.2.3 Qualiatative information

The qualiatative data collated does seem to show a difference in understanding and interpretation of death between the bereaved and control children. None of the control children were actively religious, and only two of the bereaved children belonged to a faith (Catholic). However in response to the question, *"What happens to people after they die?"*, 4 of the control children mentioned going to Heaven or Hell, whereas 10 of the bereaved children talked about spirits going to Heaven. One girl said, "Their spirit goes to Heaven, a bit stays there and other bits go to the people who loved them." The other control children gave a variety of answers, 4 said they didn't know, 2 said they just rotted, and 4 said they got buried.

In response to the question;

"When somebody dies do the sad feelings people have ever go away?"

Only 1 child in the control group said "no" and another said that "they would always remember the person, but not feel as bad". When a time scale was given, the feelings were estimated to last from a few weeks to a year. In the bereaved group, 2 children said that they didn't know if the feelings would get better, and 2 said an unequivocal "no" they wouldn't. The other children said that the feelings would get better, but gave timescales reflecting the depth of pain they felt, "a long time", "4-5 years" and "10-20 years".

When the children were asked if they felt different to the other children, 9 of the control children said "no", 2 said "slightly, as everybody is a little bit different to everybody else" and 1 said "yes" because he got hay fever. In contrast, only 4 of the bereaved children said "no" they didn't feel different, 2 said "sometimes" and 6 said "yes", with the comments, "I can't say, I did this with my Dad", "I feel jealous of the children with 2 parents, and find it hard to treat them nicely" and "I'm the only one in my class without a Dad".

The children were asked if they found 'death' difficult to talk about. In the group of control children, 6 said "yes", 2 said "no", 3 said "sometimes" and 1 said that "some people may find it difficult". Of the bereaved children, 6 said "yes" qualifying this with comments like, "a little, if I don't feel like it, and if it was recent". The remaining 6 children said "sometimes" and some gave comments, "when I'm not upset", "It's not always difficult to talk about it. After you've talked about it, it gives you time to think" Another child said "It's not hard to talk about if the other person understands death and takes it seriously. It's hard to talk to my friends".

4.3 The Mourning Bridge

Due to missing data, and the lack of understanding of the scale by 2 of the youngest of the bereaved children, there were only 7 parent-child dyads who had completed the scale at all three of the data collection points.

The distance between the two marks each person had made on the scale, represented the measure of how far across 'the mourning bridge' they had progressed. The data obtained from the mourning bridge scale was analysed using the Spearman Rank correlation. This non-parametric statistic was selected due to the small sample size. First, the actual distances 'travelled' along the mourning bridge were analysed for each parent-child dyad, to see if there was any relationship between their self-perceptions of their grief.

$r = 0.466$ $(n = 7)$ This was not significant.

Then the *amount of change* in the participants' perceptions of their grieving between the pre- and post- intervention scores (difference 1), and between the post-intervention and follow-up measures (difference 2) for each dyad were analysed to see if the direction and amount of change between the parent and child dyad scores were related.

After the groupwork all but one of the dyads' scores showed an increase in distance travelled across the mourning bridge. But the correlation was not significant;

$r = 0.51$ $(n = 7)$

The post-intervention data collection point occurred just after the anniversary of the parental death in the family which didn't 'progress across the bridge', and the surviving parent's mother had

just been hospitalised having suffered a heart attack, the cause of death of the parent.

Looking at difference 2, the *change* in scores between the post-intervention data collection point and the follow-up data collection point, all of the adults and children recorded a negative score. In other words, they perceived their grief as being more intense than at the post-group stage and had in effect moved backwards along the bridge. Despite this consistent pattern the Spearman Rank correlation was not significant;

$$r = 0.58 \quad (n = 7).$$

Any relationship would have to be very strong to achieve significance with such a small sample size.

4.4 Satisfaction of the participants

Children

On a five point Likert type scale, 6 of the children reported that they had found the group very helpful, 4 found it fairly helpful and 2 said that it had helped a little. Seven different activities were selected as the most enjoyable by the children, and 8 different activities were reported as being the least enjoyable, which showed that the spread of activities had catered for the different levels and needs of the participants. They were all able to give an example of something which they had learned through attending the group. Seven children said that they now felt it was alright to cry, 2 children felt that they had learned not to put barriers up, but to talk, and 2 had learned about the body from the doctor's session. All of the children felt that the group had been helpful, for a variety of reasons; because it had shown that there were other children around like themselves, it had made them feel better and it had demonstrated that there may be other feelings around apart from sadness. Two of the older children commented that they felt it was more suitable for the younger children.

The final question, aimed principally at re-orientating the children to their normal activities, asked what they were most looking forward to. Five of the children said coming back to the group before Christmas.

Parents

Eight of the children's parents returned their postal satisfaction survey. On the 5 point Likert type scale, all of the respondents

replied that their children had enjoyed the group 'a great deal'. Six said that they felt their children had benefited 'a great deal' and 2 said 'fair'. The parents rated the skills of the facilitator as excellent. All of the parents who responded said that they would recommend Winston's Wish Bereavement Group to someone else in their situation. Seven of the parents felt that the group had been helpful in increasing their child's acceptance and understanding of the death. Six of the parents reported that their child's school participation had improved. Three parents reported no improvement in their child's ability to talk to them about the deceased parent. Two parents commented that regressive behaviours evident since the death had improved, although another 2 parents noted that their child's fears had not improved. The general comments given by the parents were positive. One felt that she would have liked her children to have had the experience earlier, that is 3 months after the death of her partner. Two of the parents suggested that a group should be run for parents, to reduce their sense of isolation, and to help them adequately support their children.

In summary, the bereaved children were significantly different from the comparison group, in terms of their behaviour prior to the groupwork. This difference was eliminated following the intervention, due to an increase in the scores of the bereaved children. The children's understanding of the concept of death was almost at the 'ceiling' level prior to the intervention, independent of whether they were experienced with death or not. The bereaved children tended to predict a shorter life span than the comparison

group, although this difference was not significant. The predicted age of mortality increased for the whole sample of children between the pre- and post data collection points. The Mourning Bridge produced some interesting data, but despite the consistency in the perceptions of the parent-child dyads as to whether they were progressing or not in their grief, the associations were not significant, which may be attributable in part to the small sample size. The children and parents seemed satisfied with the intervention, with some helpful comments to guide future work in this area.

Chapter 5

Discussion

5.1 *Discussion of each hypothesis*

Hypothesis 1

"Children who have not been bereaved will show fewer psychological symptoms, as measured by the Behaviour Rating Form (BRF), compared to the bereaved group."

This was confirmed by statistical analysis of the BRF data, which revealed a significant difference between the bereaved and comparison groups at the pre and post intervention data collection stages. The two groups were most distinct in terms of their behaviour prior to the intervention, when the bereaved children rated themselves as exhibiting more dysfunctional behaviour. The large standard deviations of the childrens' pre intervention ratings indicated that individual differences in behaviour were quite pronounced. Indeed, to achieve such a high level of significance ($p<.001$) with a small sample size and large standard deviations indicates the strength of this finding. The differences in behaviour ratings between the bereaved and comparison groups confirms previous studies which have demonstrated that bereaved children show dysfunctional behaviour (Silverman and Worden, 1993; Elizur and Kaffman, 1982, 1983).

The behaviour ratings of the bereaved and comparison children were still significantly different at the post-intervention data collection point, albeit at a reduced level of significance. This difference was no longer evident at the 4 month follow-up. The

reduction of problem behaviours in the bereaved group could be attributed in part to the intervention, although its continued improvement following the end of the groupwork may implicate other social or familial factors. Neither of the groups' scores varied significantly over time, although inspection of the mean scores (Figure 1) shows that the bereaved childrens' scores improved at each data collection point, whereas the scores of the comparison group remained fairly stable throughout.

Previous work has suggested that grief in children may last longer than grief in adults (Silverman and Worden, 1991). It has been shown that there may be a average delay of 4-5 years before referral to professional services for help (Rutter, 1966). Thus it would be interesting to follow-up these participants over a longer time period to see if the self-ratings of their behaviour remained at a level below the 'normal' behavioural functioning of non-bereaved children. It may be that bereaved children continue to exhibit distress for a much longer time period than would commonly be assumed. They may always function differently from non-bereaved individuals, due to the constant renegotiation of their relationship with their dead parent (Silverman, 1987).

Hypothesis 2

"Those bereaved children who have already received an intervention will show a better adjustment to bereavement than children who have been bereaved but have not been involved in individual grief work, as show by the BRF and the Mourning Bridge."

This hypothesis was testing the assumption that children who

had previously been seen by the Palliative Care Team would be coping better than those children who had not received any intervention following their bereavement. The analysis found no significant differences between the BRF scores of the two sub-groups of the bereaved participants. However, visual inspection of the data (see Figure 2) shows that those children who had previously received help did initially rate themselves as having fewer behaviour difficulties than those who had not. The data obtained from the Mourning Bridge Scale was insufficient for separate statistical analyses between the two groups of bereaved children.

Hypothesis 3

"Attending a bereavement group will enable children to cope better with the loss of a parent, resulting in fewer behavioural difficulties following the group work, as measured by the Behaviour Rating Form."

At the post-intervention stage, the children who had not previously had professional help showed more improvement in their behaviour, to a level above the adjustment achieved by those who had had help. This improvement increased at the 4 month follow-up, whereas the behaviour of the children who had previously received professional help remained fairly stable across all of the data collection points. The children who had not been seen before clearly benefited from the groupwork. The somatization subtest of the BRF showed the most improvement in the bereaved childrens' scores over the duration of the study. It may be that medical information provided in the groupwork, and the normalisation of the

childrens' grief reactions contributed to this reduction in the physical expression of grief. In all of the cases where the children had not had any previous intervention, the parent had died suddenly. Lundin (1984) found that respondents who experienced a sudden death had significantly more somatic illnesses in comparison with persons who had experienced an anticipated death. Thus the difference in expectancy of the death between the two sub-groups of bereaved children may be responsible for their different rates of behaviour change.

The children who had received professional help only showed minimal improvement in the self-ratings of their behaviour on the BRF. It had been presumed that they would benefit by being given the opportunity to meet other children who had been through a similar experience to their own, thus reducing their sense of isolation and 'differentness' to other children. The lack of improvement in these childrens' behaviour difficulties may be due to differences in the surviving parents' coping abilities. For example, half of the children who had previously received help were bereaved of their mothers, whereas in the group who had not previously had professional help, all were bereaved of their fathers. Silverman and Worden's study (1993) demonstrated that men and women perceive family coping styles differently, with surviving mothers generally displaying greater competence in overall coping ability than fathers. The authors of the above study also noted that fathers reported having the most to learn when they assumed the role of single parent and took responsibility for their children's daily care. However, this is in direct contrast to

the findings of van Eerdewegh et al (1985), who commented on the "deleterious influence of the loss of the father (or being raised by a widowed mother)" (p. 193). Confounding variables such as continuing economic stability of the family may have produced such conflicting conclusions, although in the present study the number of participants was too small to include these variables as factors in the analysis.

Hypothesis 4

"Children who are bereaved and are experienced with death, will have a more complete understanding of the concept of death and grieving than the comparison 'inexperienced' children"

The childrens' understanding of the concept of death was almost complete prior to the intervention, independent of whether they were experienced with death or not. This is consistent with findings of previous research (Kane, 1979). Those children experienced with death showed no increase in understanding of the dysfunctionality, or insensitivity of the dead, concepts which were fully attained by the age of 11 years in Kane's (1979) study. Indeed comments from the bereaved children confirmed their belief in their deceased parent's ability to see and feel what was happening. One girl said, "She listens and watches over me from a cloud", whilst another commented about her Father, "He can see what I'm doing". These two participants felt that this was positive in that their parents were 'looking after them' in some way. This continued attachment to the deceased has been reported by other workers. Silverman and Worden (1993) found that eighty one

percent of the children in their study felt that their dead parent was watching them, half of whom had been frightened by this experience.

Despite the absence of religious affiliations prior to the death of their parents, the bereaved children were more likely to comment that people go to a specific place after death, particularly Heaven. This difference may be attributed to the explanations given to the children following the death of their parents. But it again reflects the desire of the bereaved children to remain connected to their deceased parent, by visualizing the dead as spirits 'living' in another space. Four of the comparison children mentioned dead people 'going somewhere', although they either didn't know where, or they said that it depends what you believe. The other inexperienced children gave more concrete responses, such as dead people 'just get buried', or 'they rot'. Such consequences were not entertained by the bereaved children as they were probably too brutal in their finality, and were not what the children wanted to believe.

The differences between the bereaved and the comparison children in the predicted age at which they would die were not statistically significant. However, the mean ages given by the bereaved and comparison children differed by more than 10 years at the pre-intervention data collection point. The large standard deviations in the data and the small sample size may have prevented this difference from reaching statistical significance. Some of the bereaved children quoted the age of their deceased parent as the age at which they thought that they too would die.

Cain et al (1964) stated in conclusion to their study of sibling bereavement, that "the children were often convinced not only that they too would die, but they would die....at precisely the same age...as the dead sibling."(p.747). Such anniversary reactions may be common in 'normal' bereavement, as children re-negotiate the loss during the course of their lives. A sense of a foreshortened future has also been found in the disaster literature (Terr, 1983). This difference in perception of the future was not apparent by the follow-up stage of the study. Perhaps with the reduction in somatic concerns of the bereaved children, the notion of foreshortened future had also been dispelled. It may be interesting to study whether the childrens' predicted age of mortality is related to their perceived health status.

The children did not seem to be adversely affected by talking about death, giving carefully thought out replies to the questions. The non-bereaved comparison group appeared to find the questions more difficult to respond to, with two of the children commenting that they had not really thought about issues concerning death very much. In contrast, the bereaved children were forthright with their replies, welcoming the chance to be listened to.

Hypothesis 5

"The surviving parent's adjustment to bereavement will be correlated with their child's level of adjustment as measured by the mourning bridge"

Only seven completed sets of data from the bereaved parents and their children were available from all three time intervals. The

correlation analysis did not yield significant results. Despite this the relatively crude visual analogue scale did show that the patterns of grief in all of the parent-child dyads varied in the same direction. After the intervention, all but one of the dyads reported that their grief had 'progressed' along the bridge, whereas at the follow-up stage, all respondents rated their grief as more acute. These variances may reflect temporary changes in response to the support offered by the intervention, with a corresponding relapse following the withdrawal of support. However, the measure indicates that the surviving parent and child responses are closely related.

5.2 *Discussion of the Methodology*

Selection of participants

Essentially the sample of bereaved participants included in this study were self-selected. The author is not aware of any potential participants who were approached, and subsequently declined to be involved in the groupwork. All of those who wished to participate in the groupwork were also willing to take part in the study. Some professional 'gate-keeping' was certainly apparent, with some people who were working with children who fulfilled the criteria for inclusion into the study, declining to approach them about the programme. Selection biases may have operated in the surviving parent's decision of whether or not to encourage their children to participate. The childrens' willingness to attend may also have been affected by factors such as personality, which may have introduced a bias in the sample population. Stroebe and Stroebe (1993) studied selection biases in their study of young bereaved widows and widowers. They found that the widows who refused to participate were less depressed than those included in the sample, but this pattern was reversed for widowers. The authors attributed this difference to gender norms governing self-control of emotion in the Western culture; males being less likely to display help-seeking behaviour if they feel that they may breakdown during the interview. Such a bias would affect the children available for inclusion into the study, with those families in which the mother has died and the surviving parent is not coping well, potentially not coming forward to participate.

The children who did participate in this research reported that the most difficult part was coming along on the first day. This is understandable as many people feel uncomfortable when they first enter a room of strangers. Perhaps those children who are shy and most isolated would find this barrier too large to overcome. If this were so, one of the main aims of attending the group, that is to reduce the childrens' sense of isolation and being 'different', would not be available to the children who are in most need of this help. However, the low rate of attrition in this study, in which only one child (8%) failed to attend after the first day, compares well to other studies in this field, such as Black et al (1983) in which the attrition rate was 50%. The low 'drop-out' rate in the present study may have been due to the compact nature of the intervention, which did not require an ongoing regular committment. Alternatively, the procedure designed to engage the participants may have been extremely successful. This involved a domiciliary visit to meet the whole family. In addition to serving the function of information gathering prior to the intervention, this visit also gave parents the opportunity to meet one of the people who was going to work with, and be responsible for their child over the duration of the intervention. In addition to this, the meeting also enabled the children to meet someone who would be involved in the group work, thus reducing their apprehension in coming along to the group for the first time. Although this procedure was fairly time consuming, it seems to have played a valuable role in enabling the children to attend.

Due to the small number of participants in this study, the sample

cannot be assumed to be representative of bereaved children in general as selection biases, both of parents and children cannot be excluded. A larger sample, or replication studies, would minimise the effects of individual differences and provide information that would be more generalisable to the population of bereaved children as a whole.

Design

This study incorporated a cross-sectional design. From such a 'snapshot' of the bereavement process, conclusions can not be made about the effectiveness of the intervention on adaption in the longer term. The current study indicates that the behaviour of the bereaved children improved after the intervention, and that this improvement was maintained at the four month follow-up. However, a longitudinal study with a bereaved control group would enable inferences to be made about the 'buffer' effect of a preventive intervention in reducing the development of maladaptive coping responses.

Grief is a complex phenomena which involves affective, physiological, cognitive, behavioural and social symptoms (Stroebe and Stroebe (1987). There have been significant advances from intra- to interpersonal models of bereavement and from clinical to much broader biopsychosocial approaches to the study of grief. Focusing on the single event of the parental death, without studying the social and environmental context of the children's responses, may have over-simplified the bereaved individual's

situation (Berlinsky and Biller, 1982). Brown et al (1986) used the concept of 'increased vulnerability' to describe the effects of loss in the adult women he studied, emphasizing that bereavement should be studied within the context of other life-events and situations. This notion supports the Time-related model of Baker et al (1992), which considers the bereavement in the light of the other developmental tasks which face the child.

Often 'symptoms' of grief change over time, with the yearning and searching behaviours seen during the early protest stage being replaced by withdrawal and apathy in the later despair phase. So the presence and absence of symptoms, as measured by the Behaviour Rating Form, may also over-simplify 'recovery', with different behaviours indicative of different phases of grief. The changing nature of the concept of grief is problematic for its assessment in that measures may indicate an improvement in grief, whereas the symptoms may simply have changed. Measures may not be grief specific, but may measure reaction to loss in general. Behaviours commonly seen in grief may also be markers for other clinical conditions, such as depression, thus making the development of standardised measures with discriminative validity more difficult. Also quantative assessments tend to concentrate on symptomatology, that is, negative emotional states, whereas it may be more profitable to also highlight the capacity of individuals to cope, and thus provide information about factors which promote 'recovery'.

5.3 *The Evaluation Package*

One of the aims of the study was to develop a comprehensive package for evaluating the effectiveness of an intervention with bereaved children. Five measures were used in this study.

1 Behaviour Rating Form

This measure yielded useful data during the study. All of the children could understand the questions, and found the Likert type scale easy to use. The reliability and validity of the measure would be strengthened if it had been piloted on a larger population to ensure standardisation. Concurrent validity with established standardised measures was difficult to obtain, as in the knowledge of the author, no measures which incorporate self-ratings by the children exist.

The main analyses were conducted on the childrens' self-ratings of their behaviour, in contrast to Silverman and Worden's (1993) study, which utilized the parents' ratings of their childrens' behaviour. Several authors have commented on the inaccuracy of parent's perception of their children's subjective experiences (Herjanic, 1984) and more specifically their tendency to underestimate the extent and severity of the children's reactions to loss (van Eerdewegh et al, 1985; Blank, 1975). In their study of 350 widows and widowers, Shucter and Zisook (1993) reported that 56% of the participants felt that the children were coping better 2 months after the bereavement of their parent than before the death. A full description of the population was not given in this paper as it had been reported previously (Zisook et al 1990), but

as participants were engaged via death certificates, the mode of death may well have been a mixture of sudden and expected circumstances. It seems incredible that so many participants should perceive that their children were seemingly unconcerned by the death of their parent. The authors fail to comment further on this finding in the paper. In the present study the bereaved childrens' self-ratings and their parents' ratings of their behaviour have been diagrammatically represented (figure 4). Although data was missing from the parents in 5 cases, it can be seen that the parents who did not fully complete the questionnaire, were related to children who reported their own behaviour as being much more dysfunctional than the other bereaved children. This may suggest a tendency to minimise or deny their children's difficulties, and supports the observation made by Van Eerdewegh et al (1982) commenting on their research, that despite an increase in symptomology of the bereaved children in comparison with the control children, fewer physician visits were made to the bereaved children. The difference in perceptions of parents and children of the latter's coping seems an interesting issue which should be studied further.

II The Mourning Bridge

The concept of this visual analogue scale was too complicated for the younger children to understand. They did not have the conceptual understanding of grief, as a collection of feelings, changing over time. Perhaps this can only be fully understood after the experience of the resolution of bereavement, when the bereaved

know that the turmoil of acute grief does not last indefinitely. Some children reported on the Comprehension of Death Questionnaire, that the sad feelings people have after someone dies probably last 4-5 or 10-20 years. In the light of these predictions it must have been very difficult for these children to imagine not feeling pain about the loss of their parent.

The adults in the study did understand the conceptual task required by the Mourning Bridge measure and were able to relate this symbolism to their own grief. One parent commented that he felt 'one brick back' from how he had felt on the previous data collection point. However, because grief is not a stable emotional state, but a plethora of emotions affected by internal mood, personality factors and external situational cues, parents reported that their perceptions of their own grief changed on a daily, or even more frequent, basis. The similar pattern of scores from the limited data available supports the notion of parent and child patterns of grief being related. Perhaps with a larger sample size a significant association would have been found.

III The Comprehension of Death Questionnaire

This measure may have been more useful if the age range of the intervention had been extended to accommodate younger children. Most of the children included in this study had a fairly complete understanding of the components of the concept of death prior to the intervention. The effect of 'experience with death' on the acquisition of the components of the concept of death could not be elucidated. Some interesting data did emerge from this

questionnaire, such as the bereaved children's sense of a foreshortened future. This may be related to their perceptions of their own health status, and somatic complaints, and also has implications for anniversary reactions (Fox, 1985), particularly when they reach the same age as their deceased parent. The childrens' beliefs about what happened after death also differed between the bereaved and comparison groups, emphasizing the need of the bereaved children to remain connected with the parent who had died.

One difficulty with the measure, which was based on previous work (Kane, 1979), was that the childrens' answers were scored according to whether they held 'notions like those of an adult'. As far as the author is aware, no studies have been undertaken into adult's understanding of death. It is likely that this construct is affected by other variables, such as religiousity and culture, and may therefore vary even amongst adults. The effect of these factors should be considered in further development of an effective measure.

IV The Parental Interview

This measure was included primarily as a clinical tool, in order to obtain background information about the family circumstances of each of the bereaved children prior to the intervention. Silverman and Worden's (1993) study incorporated more formal standardised measures to assess factors such as the family structure and coping, social support networks, health status and coping ability of the surviving parent, for each of the participants

in their study. An extensive formal assessment of this nature has the advantage of quantifying these variables, thereby enabling possible interaction effects between these factors and 'recovery' after a bereavement to be studied. This would give added information about which features of the bereaved children's situation increased their vulnerability to the experience of loss, or slowed down their subsequent adjustment. In the present pilot study, it would not have been feasible to carry out such an in-depth study of these potential risk factors, due to the small sample size and inevitable individual differences which would have made 'real' associations between variables very difficult to discern. However, the possibility that variations in these contextual factors may have contributed to the differences found between the two sub-groups of the bereaved participants cannot be excluded in this study.

V Satisfaction Questionnaires

The childrens' responses on the satisfaction questionnaire showed that they valued the intervention and the opportunity to meet with other children who had also been bereaved of a parent. The question asking the children what the most enjoyable activity had been, received a wide range of replies. Almost half of the group stated that the 'fun' activities, such as the kick rounders played in the breaks had been the most enjoyable. The others focused more on the actual grief-related activities, such as the candle ceremony, or talking about their deceased parent. The different activities which appealed to the children, reflect their

varying needs, such as saying goodbye, or increasing their self-esteem. This indicates that any service which is developed to work with bereaved children must have a range of activities or interventions on offer in order to cater for all of the childrens' needs.

The parents' replies to the satisfaction questionnaire were very positive in that all of the respondents felt that their children had benefited from the group work. The suggestion of two of the parents for a similar intervention for themselves should also be borne in mind in future service development. Without the support of parents, children are unlikely to progress through the grieving process (Furman, 1974).

5.4 *Conclusions*

In conclusion, the findings of this study indicate that very real differences exist between the behaviour of bereaved children in comparison with matched non-bereaved children. The study does not demonstrate that a bereavement affects the acquisition of a concept of death. Although a bereavement may affect the childrens' perception of events following death. This may indicate their need and desire not to let go of their relationship with their dead parent. Further research matching the cognitive abilities of the bereaved and comparison children rather than their ages may produce different results.

The study tends to support the inter-dependence of the children and parents' grief reactions and thus emphasises the need for all of the family members to be supported. The qualiatative data supports the success of the programme in giving the children permission to talk about their loss, and normalising their situation. The intervention incorporated rituals whereby the children could 'say goodbye' to their dead parent, but also provided the means for them to legitimately remember the deceased.

Some studies (Brown and Harris, 1978, Caplan, 1961) have suggested that the most 'dangerous' life-events, in terms of subsequent onset of mental illness, are characterized by three criteria. Such events require people to undertake a major revision of their assumptions about the world, they represent permanent changes and they take place over a relatively short period of time. Clearly a parental death could be construed as a 'dangerous life

event', presenting children with the need to radically rethink their assumptions about the world. In the light of this, a preventive intervention in the early stages of grief is clinically valid. The lack of services for this client group is being increasingly recognised, with the bereavement counselling service CRUSE recently publishing a pamphlet giving advice on supporting bereaved children (1993). In the eight months since the completion of this pilot study the service has received 72 referrals of bereaved children from a variety of sources. Many of these referrers have expressed relief that at last some support is available. Informal social support networks in the 1990s can no longer be assumed to provide adequate support for bereaved people (Lopata, 1993, Rosenblatt, 1993). Indeed, the enthusiastic response to the establishment of a grief support programme for children certainly indicates that this has been a much neglected area which deserves further study and refinement, to ensure that the most effective support is offered to those most at risk.

5.5 *Recommendations for Future research*

Several authors have questioned the aim of bereaved individuals 'recovering' being equated with a return to their pre-death level of functioning. Silverman (1988) and Weiss (1993) have argued that bereaved people never recover, but are changed in certain ways. This is consistent with the view that children re-negotiate the loss of a parent throughout their lives, as its relevance to their own life tasks changes (Silverman and Worden, 1991). Perhaps outcome measures should be concentrating on measuring adaption, which is more consistent with coping models of bereavement (Lazarus and Folkman, 1984). This approach would attempt to isolate factors which place the individual at increased risk of long-term emotional difficulties following a bereavement. Such factors may include predisposing situational characteristics, for example, the lack of social support, poor health status or perhaps certain personality traits. Other factors may be implicated in prolonging grief, such as isolation, social stigma surrounding the death and so on. If these risk factors were known then treatment could be targeted at those individuals with an increased likelihood of a poor outcome.

Longitudinal studies may be able to clarify the 'recovery' criteria of bereavement, that is, what constitutes good adjustment to loss. Such long term studies may also indicate whether early intervention reduces the disproportional referral rate of bereaved children some years following the parental death (Rutter, 1966).

Further work is also required in the development of effective measures which can discriminate between grief and other

difficulties. The Texas Revised Inventory of Grief (TRIG - Faschingbauer et al, 1987) which assesses grief reactions in adults is able to differentiate between depression and grief, but no such measures exist for children. The assessment of family reactions and their interplay (Fairchild et al, 1991) is clearly important as grief in children is moulded to some extent by the communication patterns in the family and the reactions of the surviving parent.

Research with bereaved children is a growing field of study, with increasing numbers of questions to answer. The encouraging increase in motivation to develop services for bereaved children must be based on a strong research foundation. Indeed much of the current literature still does not address the evaluation of specific interventions with children and young people.

5.6 *Suggestions for Future Service Development*

The themes which have emerged in this research and in recent literature (Stroebe et al 1993) seem to support a coping model of loss and a need to study adaption rather than recovery. The children felt that they benefited from activities which served to increase their self-esteem and gave them permission to express their grief. Both of these factors may have positive effects on the childrens' coping abilities. Clearly a family approach is crucial in order to assist bereaved parents in dealing with their own grief and enabling them to provide adequate support for their children.

Teaching and training could be offered to the Education services, to increase their awareness of the difficulties and potential issues which bereaved children may face on their return to school. Familiar teachers, and the routine of school, often maintain childrens' sense of security and stability in such a time of crisis. The use of carefully selected and trained volunteers and an increased understanding in professionals who would normally have contact with the children, helps to prevent the pathologising of grief and would make the service less threatening to potential service users (Parkes, 1993).

As a result of this pilot study, a programme has evolved encompassing a comprehensive grief support programme for children, young people and those who support them. It has several 'levels' of intervention in terms of the intensity of the grief work, the focus on factors which facilitate coping and the agencies involved in providing this.

A - SERVICES TO CHILDREN AND YOUNG PEOPLE
Camp Winston - A two day residential programme After School Groups - For ongoing support Individual Work Pre-school Programme - For children aged 3-5 Outdoor Education Programme - For enhancing self-esteem Social Programme
B - SERVICES TO PARENTS
Individual work Groupwork Ongoing support group
C - SERVICES TO EDUCATION AND TRAINING
Developing a de-briefing service following a death in school Training key workers/link people in schools

Table 6 A proposed bereavement service for children, young people and those who support them.

The development of such a comprehensive service would provide an innovative approach to health promotion. Further research is needed to ensure that it meets the needs of children who have experienced the death of someone important in a creative and constructive way.

APPENDIX A

Cheltenham & District and Gloucester Health Authorities

Psychology Department
10 West Lodge Drive
Coney Hill
Gloucester GL4 7QJ
Tel.: Glos. (0452) 614101

Our ref:

Your ref:

28th August 1992

Dear

The Gloucestershire Royal Hospital is always seeking to improve and develop its services to patients and their families.

We are currently planning a study of the effectiveness of doing grief work with children in order to pilot a new bereavement service. Ten children, aged between 8-12 years old, who have lost a parent in the last 2 years by sudden or expected death will be involved in a bereavement group. The group will meet for 2 days during the school half-term, in the last week of October 1992, with a 'booster' day approximately 6 weeks later. The group will involve creative play, sharing, games and familiarisation with the hospital.

The aims of the group work are:

1. To normalise the grieving experience for the children by offering them information and the opportunity to identify with other children coping in a similar situation.

2. To help the children express the effects of the loss and to voice any fears or concerns they many have.

3. To recognise the children's individual relationship with the deceased and to encourage a healthy separation.

4. To prevent anxiety associated with hospitals or doctors by taking the child to visit hospital and to talk to a consultant who will answer their questions.

If you feel that this bereavement group would benefit any of the families attached to your practice then please could you pass on my telephone number to them, or alternatively pass on their names and addresses to me before the end of September and I will arrange a visit to discuss it with them. If you would like more details then please do not hesitate to ring me.

Thank you for your help.

Yours sincerely,

Nicola Hardy, Trainee Clinical Psychologist.

If you call or telephone ask for

_____ Ext. _____

Our Ref.

Your Ref.

Gloucestershire Royal Hospital
Great Western Road
Gloucester GL1 3NN

Dear

The Gloucester Royal Hospital is always seeking to improve and develop its services to patients and their families.

We are currently planning a study of the effectiveness of doing grief work with children in order to pilot a new bereavement service. Ten children, aged between 8 - 12 years old, who have lost an important person in the last year, will be involved in a bereavement group. The group will meet for 2 days during the school half-term, in the last week of October, 1992, with an extra day approximately 6 weeks later, and will involve creative play, sharing games and familiarisation with the hospital

The main aim of the group work is to help the children to cope with their grief.

If you feel that your child could benefit from participating in this group and you would like more information, then please return the strip below in the S A E provided and I will contact you.

Thank you for your help,

NICOLA HARDY, Trainee Clinical Psychologist

JULIE STOKES, Principal Clinical Psychologist

NAME ..... Tel. No. .....

ADDRESS .....

.....

.....

CONTENIENT TIMES TO CONTACT YOU ARE .....

.....

.....

1/0H

If you call or telephone ask for

_____ Ext _____

Our Ref.

Your Ref.

GLOUCESTER
HEALTH AUTHORITY
The Chair: Ms Rennie Fritchie

Gloucestershire Royal Hospital
Great Western Road
Gloucester GL1 3NN
Tel. No. Gloucester 28555

Glos 528555 extn 4377
Mornings only

Dear Parent

Just to let you know some final details regarding the bereavement group taking place in half term. We have decided to start the group at 9 o'clock on Monday and Tuesday - in case any parents need to be at work. Please bring your child/children to the Health Psychology Department at the hospital (map enclosed). Unfortunately parking is very difficult but you may be able to double park and quickly drop in to the health psychology department. The first day will end at 5.30pm. On Tuesday we would like to invite you to attend a brief meeting for parents. This will take place at 2pm in Social Services (just down the corridor from health psychology). We would like to meet you to let you know what the children have been involved in over the two days and also answer any questions you might have in supporting your child/children with their grief. We would then invite you to join in a closing ceremony which will end about 4.30pm.

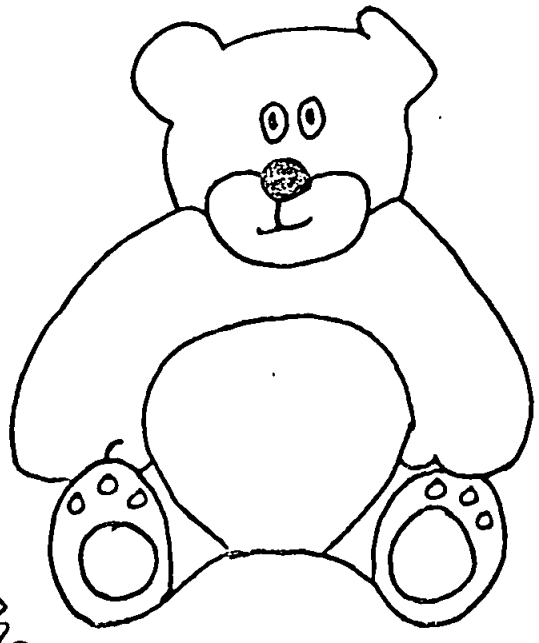
If you are unable to attend the parents meeting please could you let me know.

I look forward to meeting you soon,

With best wishes

Julie Stokes
Principal Clinical Psychologist
Palliative Care Team

WINSTON



The bear who cares

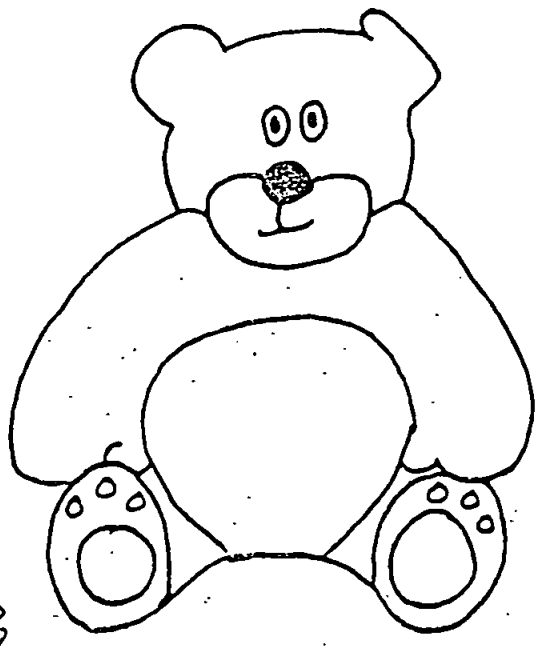
Dear

We are looking forward to meeting you on nday and Tuesday 26th and 27th October. There ll probably be about 10 other children in the group. All e children who come to this special group share one ng in common - someone important in their life s died.

We have lots of exciting things planned which we e you will enjoy and find useful. Please bring photo of your dad to the group.

Bye for now

WINSTON



The bear who cares

Dear

It was lovely to see you in October. We hope that you enjoyed Winston's group.

We would like you to come back and join the other children again for a Winston's Wishes Christmas ceremony on the 18th December. This will be held from **5:00-6:30pm.** in the Chapel at Gloucester Royal Hospital.

We have a few things planned which we hope you will enjoy and find useful. Please bring your Dad along, and your special Winston candle.

Bye for now,

Dianna

Nicky

Tel: 0452 614101

Psychology Dept.,
10 West Lodge Drive,
Coney Hill,
Glos.

Dear

I would like to take this opportunity to thank you and for participating in my research. I hope that you enjoyed the Winston's Wishes Group, and found it helpful. The service is now being developed further and, pending confirmation of a grant, will be established as a service for the bereaved children of Gloucestershire.

During Winston's Group I took a few photographs of some of the activities that we undertook and I would like to use these in two ways. Firstly, to brighten up my thesis, and hopefully 'bring the group to life' in pictoral form, as well as describing it in the text. Secondly, we have made slides from the photographs, and we would like to incorporate these into presentations about the role of Winston's Wishes and in the training of volunteers, in order to expand the service. Despite obtaining your consent to administer questionnaires, I have been informed that I need to have your explicit permission before I can use the photographs. Therefore I would be grateful if you would complete the slip below and return it to me in the SAE provided. The use of the photographs would be invaluable in promoting this work further.

Once again, thank you for all of the time and effort you have given in order to make this evaluation possible.

Yours sincerely

Nicola Hardy.

I do / do not give my consent for the photographs taken during the two day workshop to be used for promoting the work of Winston's Wishes, and to be included in the Research write up.

Parent _____ Date _____

Child/ren _____

_____

APPENDIX B

INFORMATION SHEET

The Gloucester Royal Hospital is always seeking to improve and develop its services to patients and their families.

We are currently planning a study of the effectiveness of doing grief work with children. Ten children will be involved in the bereavement group, all of whom have lost an important person within the last year. The group will meet for 2 days during the school half term, in the last week of October 1992, with a 'booster' day approximately six weeks later, and will involve sharing, drawing, games and a tour of the hospital.

The aims of the group work are;

1) to normalise the grieving experience for your child, by offering him / her information and the opportunity to identify with other children coping in a similar situation.

2) to help your child express the effects of the loss and to voice any fears and concerns he / she may have.

3) to recognize your child's individual relationship with the deceased and to encourage a healthy separation.

4) to prevent anxiety associated with hospitals or doctors by taking the child to visit hospital and to talk to staff who will answer their questions.

Because this is a research project, the study will involve you and your child responding to some questionaires. All of the responses and group work will be COMPLETELY CONFIDENTIAL.

Thank you for your help

Signed Julie Stokes, Clinical Psychologist

Nicola Hardy, Trainee Clinical Psychologist

CONSENT FORM

I have read the attached Information Sheet about the research project studying the effectiveness of doing grief work with children.

I hereby agree that my child can take part in the study, on the understanding that he / she may withdraw his /her participation at any time, without obligation. Such withdrawal will not affect any further treatment in any way.

Signed.....(parent) Date.....

I have also read, and had explained to me, the attached Information Sheet about the research project studying the effectiveness of doing grief work with children.

I hereby agree to take part in the study, on the understanding that I may withdraw my participation at any time, without obligation. Such withdrawal will not affect any further treatment in any way.

Signed.....(child) Date.....

APPENDIX C

CHILD BEREAVEMENT STUDY - GRH 1992

PARENTAL INTERVIEW

Child's name : D.O.B. Religion

Membership of the household Relationship to child D.O.B. Age

SECTION A

What was the cause of your wife / husband's death ?

If sudden death, go to SECTION B

How long was your wife / husband ill in total ?

Did you know that your wife / husband was going to die ?

Where was your husband / wife during his/her illness ?

a) Home
b) Hospital
c) Hospice

If your spouse was not at home, was the child named above able to visit their parent during his / her illness ?

How often ?

Did *the child named above* help in the care of their ill parent in any way ?

If so, how ?

SECTION B

How was your wife / husband's death explained to your child ?

cont..

When did your husband / wife die ?

Where did your husband / wife die ?

Did *the child named above* attend the funeral or cremation service ?

If YES, Why?

If NO, Why?

Other stressful events

A long term illness, and/or bereavement, may result in changes in many different aspects of family life. The grieving process may be affected by the occurrence of other life events at this time and by the person's previous experience of loss.

Has *the child named above* been bereaved before ?

How has *the child named above* coped with previous losses ?
e.g. CH (changing school), MH (moving house), D (divorce), PD (pet's death), S (separation), PI (physical injury), O (others)

Have any of the following happened in the previous 18 months ?

Have you been separated from *the child named above* through

a) Hospitalization ?

b)Long stays with relatives and/or friends ?

c)The child being taken into care temporarily ?

Have you or *the child named above* coped with any other bereavements ?

Has a family pet died ?

cont....

Have any members of the family suffered a physical injury ?

Has the family moved home ?

Has *the child named above* changed schools ?

Or had any problems at school ?

Has your financial situation changed since your wife/husband's death ?

Have you formed a personal relationship with anyone since your husband/wife's death ?

How has your child coped with forming new friendships or maintaining old ones?

Support

Who are the important people (relatives and friends) in *the child named above's* life ?

cont...

How has your relationship with your child changed since the death of your partner?

Has the child's role within the family changed since the death of your husband/wife?

How involved do you think children should be in discussions

a) Prior to death ?

b) After death ?

In your experience, what made it a) difficult

and b) easy to discuss issues relevant to your husband/wife's death to *the child named above* ?

cont....

How do you think children grieve ?

What do you think has helped you to overcome losses in your own life ?

Has your child's behaviour changed since the death of your wife / husband ?
(re: sleeping; eating; health; attitude to school; school performance; fears; mood)

If I'd met your child a couple of years ago, what would he/she have been like?

Any further comments / details....

NICOLA HARDY / JULIE STOKES

APPENDIX D

BEHAVIOUR QUESTIONNAIRE

Name .....

Date .....

Below are a number of sentences that children have used to describe how they feel and behave. Read each sentence and put a ring around the number to the right of the statement to show how you have been feeling and acting in the past week. There are no right or wrong answers. Do not spend too much time on any one sentence, but give the answer which best describes your behaviour.

	Almost never	Sometimes	Often	Almost always
1. I enjoy being at school	1	2	3	4
2. I find it hard to concentrate on doing my school work	1	2	3	4
3. I find it easy to get to sleep at night	1	2	3	4
4. I feel sick	1	2	3	4
5. I like doing what others tell me to do	1	2	3	4
6. I feel safe and secure	1	2	3	4
7. I would rather go out to play than stay indoors	1	2	3	4
8. I swear	1	2	3	4
9. I think I am clever	1	2	3	4
10. I get nervous when I have to do something new	1	2	3	4
11. I have bad dreams	1	2	3	4
12. I feel included	1	2	3	4
13. I feel it is my fault when something goes wrong	1	2	3	4
14. I find it easy to get on with my teachers	1	2	3	4

	Almost never	Sometimes	Often	Almost always
15. I eat less than I used to	1	2	3	4
16. I would rather play on my own than with others	1	2	3	4
17. I wet the bed	1	2	3	4
18. I can make decisions easily	1	2	3	4
19. I worry about things	1	2	3	4
20. I get into trouble at school	1	2	3	4
21. I cry about things	1	2	3	4
22. At times I feel like smashing things	1	2	3	4
23. I feel I have more friends now	1	2	3	4
24. I get angry with people	1	2	3	4
25. I worry about others in my family when I am away from home	1	2	3	4
26. I get picked on at school	1	2	3	4
27. I shout at friends/family (lose my temper)	1	2	3	4
28. I feel shy	1	2	3	4
29. I feel that I am not the only one with problems	1	2	3	4
30. I get on well with the other children	1	2	3	4

Scoring Key for the Behaviour Rating Form

The form is made up of 5 behaviour categories, with 6 questions in each, resulting in a total of 30 questions.

The range of total possible scores on this questionnaire is from a minimum of 30, to a maximum of 120. The range of scores achieveable on each construct is from 6 to 24. A high score represents good adjustment with respect to that particular behaviour category.

Construct	Qu. No.	Scoring			
School Work					
	1	1	2	3	4
	2	4	3	2	1
	9	1	2	3	4
	14	1	2	3	4
	20	4	3	2	1
	26	4	3	2	1
Anxiety					
	6	1	2	3	4
	10	4	3	2	4
	13	4	3	2	1
	18	1	2	3	4
	19	4	3	2	1
	25	4	3	2	1
Anger					
	5	1	2	4	3
	8	4	3	2	1
	22	4	3	2	1
	24	4	3	2	1
	27	4	3	2	1
	30	1	2	3	4
Isolation					
	7	1	2	3	4
	12	1	2	3	4
	16	4	3	2	1
	23	1	2	3	4
	28	4	3	2	1
	29	1	2	3	4
Somatization					
	3	1	2	3	4
	4	4	3	2	1
	11	4	3	2	1
	15	4	3	2	1
	17	4	3	2	1
	21	4	3	2	1

APPENDIX E

COMPREHENSION QUESTIONAIRE

How can you tell when someone is dead ?

Can a dead person.....

a) move (b) talk (c) smell e.g. flowers

d) hear (e) dream (f) think

What makes (causes) people die?

What is the difference between someone who is dead and someone who is dying ?

Does everybody die ?

How do you make dead things come back to life ?

Are people afraid of death ?
Anything in particular?

What happens to people after they die?

What is a funeral / cremation for ?

How do people feel when someone dies ?

How do people cope with the feelings they have when someone has died ?
i.e. What helps them to feel better?

Do these feelings ever get better ?

Do you feel that you are different to the other children?
If Yes,..How?

Are people always told the truth when someone dies ?
If No, when might they not be told the truth?

Is death difficult to talk about ?

How old do you think you will be when you die ?

If you had three wishes, what would they be?

NH (1992)

APPENDIX F

Instructions for completing the Mourning Bridge

Adult

This bridge symbolizes the journey through grief. This journey is from the time that you first learned of the death of your loved one, to the stage where you can remember them, both good and bad times, with some sadness but not pain. The time when you feel that you can re-invest your emotional energy into another relationship. This is seen as the end of the grieving process.

Could you put a cross along the top of the bridge to represent how you felt when you first learned that your partner had died, and another cross to show where you feel that you are now on this journey.

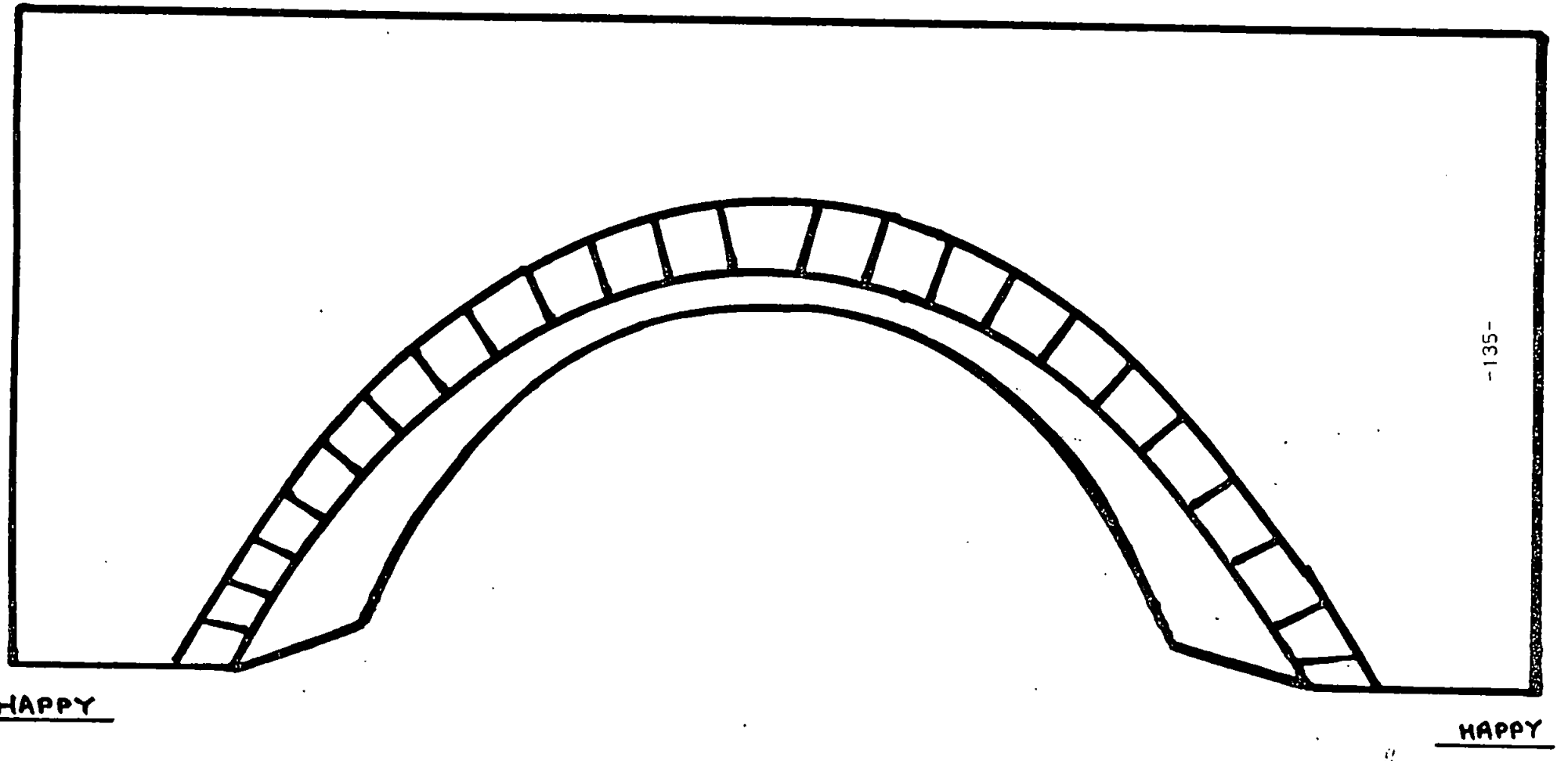
Child

When someone special dies we feel very sad. We might find it hard to talk about the person who has died or we might get upset when we remember things that we did with them. After a while, it usually gets easier to talk about our special person. We can think about good and bad memories without feeling hurt inside.

This is a picture of a feelings bridge. One side is when we are really sad and unhappy. The other side , when we have crossed the bridge, is when we can remember our special person without feeling too sad. Put a cross along the top of the bridge to show how you felt when you first heard that you special person had died. Now put another cross on the bridge to show where you think you are now.

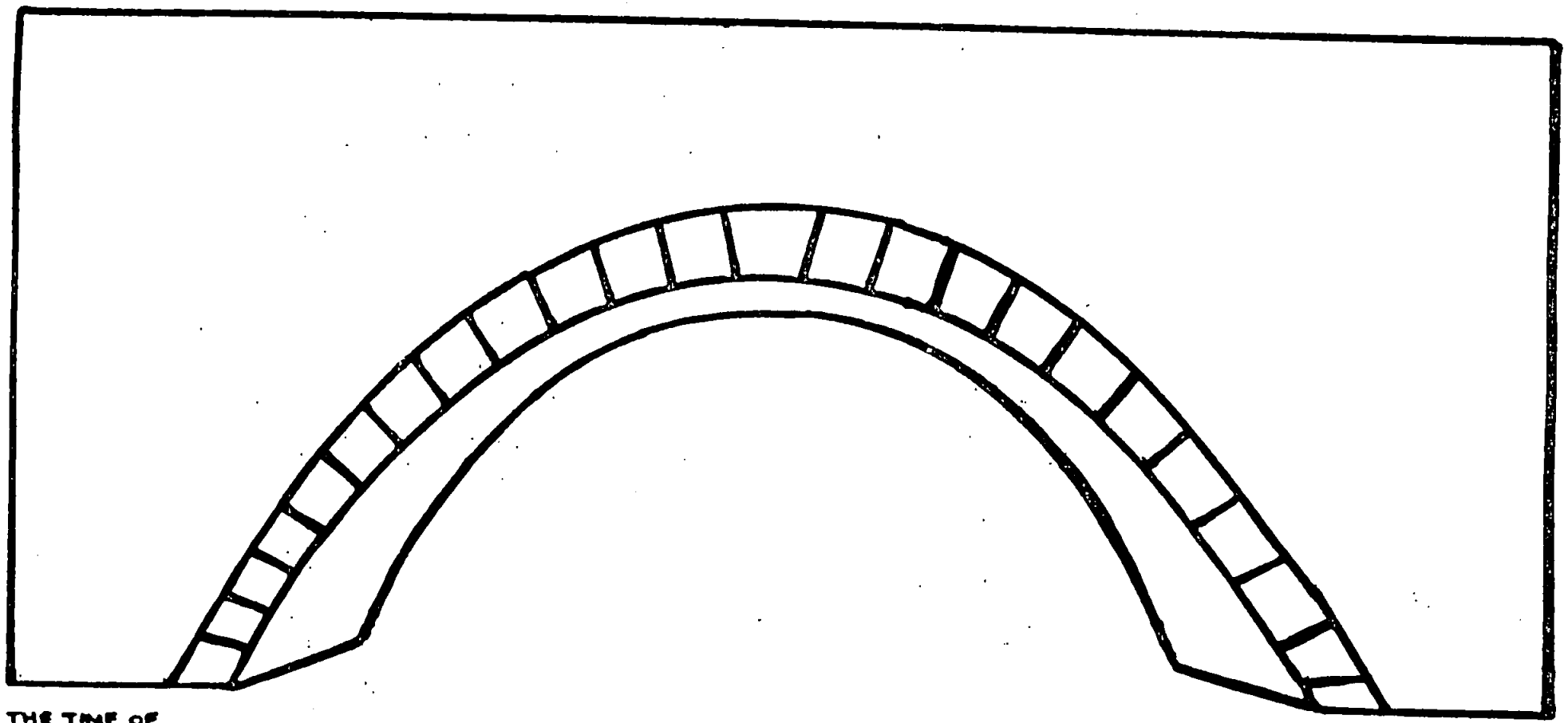
NAME

DATE



NAME :

DATE :



A THE TIME OF THE BEREAVEMENT

ABLE TO RE-INVEST EMOTIONAL ENERGY

APPENDIX G

W I N S T O N ' S G R O U P

PARENT EVALUATION

Please complete an evaluation on each child you had enrolled in the programme.

Child's Age ..... M/F ..... Today's Date.....

Please answer the questions below by checking the answer which most accurately describes your feelings.

1. Did your child enjoy attending the children's group?

A great deal	.....
Fairly	.....
To some degree	.....
Comparatively little	.....
Not at all	.....

2. Does your child feel he/she benefited from attending the children's group?

A great deal	.....
Fairly	.....
To some degree	.....
Comparatively little	.....
Not at all	.....

3. What overall rating would you give to the children's group in terms of its objective of helping your child to cope with the death in your family?

Excellent	.....
Good	.....
Fair	.....
Poor	.....
Very bad	.....

4. How would you rate the skills of the professional facilitator of your child's group?

Excellent	.....
Good	.....
Fair	.....
Poor	.....
Very bad	.....

5. Would you recommend Winston's Group to someone else in your situation?

YES ..... NO .....

6. How did you learn about Winston's Group?

.....

.....

7. Please indicate with a checkmark those problem areas where you have seen changes in your child's behaviour since he/she attended the group. (Please leave category blank if behaviour is not relevant.)

	Great Improvement	Some Improvement	Not Much Improvement	No Improvement
Understanding of death	.....	.....	.....	.....
Acceptance of death	.....	.....	.....	.....
Ability to talk about deceased parent	.....	.....	.....	.....
School (participation and grades	.....	.....	.....	.....
Relationship with siblings	.....	.....	.....	.....
Relationship with parent	.....	.....	.....	.....
Relationship with friends	.....	.....	.....	.....
Bad dreams	.....	.....	.....	.....
Fears	.....	.....	.....	.....
Aggressive behaviours	.....	.....	.....	.....
Acting out behaviours	.....	.....	.....	.....
Regressive behaviours	.....	.....	.....	.....
Other	.....	.....	.....	.....

IENTS/SUGGESTIONS :

9th November, 1992

Dear Parent

We hope that your child/children enjoyed attending Winston's Bereavement Group.

As you know, this was a pilot study to see if this way of working is beneficial to the children and it could be established as a new bereavement service. At the close of the group, we asked the children to complete a short evaluation of the two days, but we would value your views as well. You may have noticed a change in your child/children or he/she may have spoken to you about the parts of the group which they enjoyed or didn't enjoy.

We would be grateful if you could complete the enclosed questionnaire and return it in the stamped-addressed envelope.

We are planning a short 'follow-up' get together prior to Christmas which Winston will invite the children to shortly.

Thank you very much for your help.

NICKY HARDY
Psychologist

SATISFACTION QUESTIONNAIRE

Did you find the group helpful? No a little don't know fairly very

The most enjoyable part of coming to the Bereavement Group was.....

The least enjoyable part of coming to the Bereavement Group was.....

What I have learned since coming to the Bereavement Group is.....

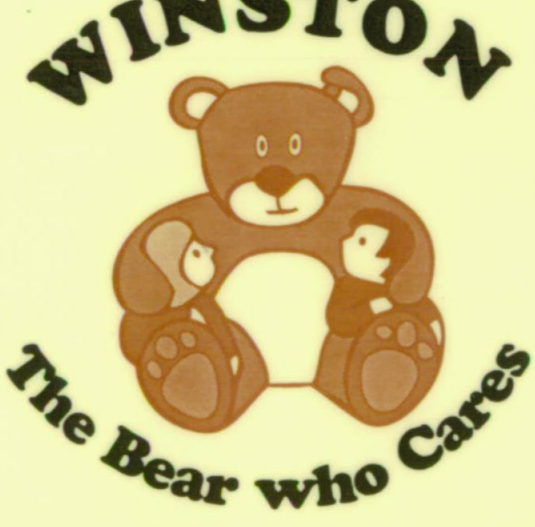
Do you think that coming to a group like this helps children? Yes / No

Comments....

What are you most looking forward to.....

GRH-PCT 1992
NH-JS

A Two day bereavement course for children



Contents

(referring to page numbers at top of document)

REGISTRATION (30 mins)

Badge-giving

Winston name badges were given to the children as they arrived on the first day of the group. The group leaders also wore these badges throughout the group sessions.

AIMS 1) These badges were bear shaped, to represent 'Winston - the bear who cares', our adopted mascot for this bereavement work.

2) The badges were emblazened with the owner's name.

3) A balloon was attached to the badge, colour coded in order to easily identify the child's loss (Fig. 1), and enable them to recognise others who had suffered a similar bereavement.

Equipment - The badges were drawn using a stencil, and then laminated to protect them. The balloons were drawn separatly and again laminated. A pipe cleaner was used to attach each balloon to the badge. A safety pin was attached to the reverse of the badge so that it could be secured on to the individual's clothing.

Photo gallery

Each child, in their formal invitation letter, had been asked to bring a photograph of the special person who had died with him/her on the first day of the group. The leaders also undertook this task. During the registration period the children attached their photographs onto the 'gallery' and labelled them, e.g. 'Beth's Mum'

AIMS 1) It was assumed that the process of selecting the photograph would require the family members discussing the deceased and perhaps looking through a photograph album together, which would assist with Worden's(1982) first task of grieving.

2) As the children individually put up their photograph, the leader asked them questions about it, e.g. How old were you at the time it was taken? Why did you choose this photograph?

3) The gallery provided an early focus for the group's identity and content, being composed of children who had all lost someone special in their lives.

EQUIPMENT - Some large sheets of card, photograph corners and a thick pen.

Individual and group photographs

Some of the activities during the intervention were undertaken in small groups, made up of children of a similar chronological age. During registration the children were introduced to the leader who would be responsible for their group, and photographs of each of the groups were taken, with their bears - Winston, Winnie or Amanda. The youngest children's group, had 3 leaders, to give a leader:child.ratio of 1:2.

A photograph of each child was also taken to put in the middle of their Winston's Wishes message mural balloon.

WELCOME (30 mins)

Introductions

The group leaders introduced themselves, by means of singing a ditty; "Introduce yourself right on, right on,

Introduce yourself right on....."

Then one of the leaders would jump forward and sing..

"My name is....., and I feel/am ....."(rhyming)

The song would then be repeated and the next leader would jump forward and complete the ditty.

Group Rules

1) Treat others with care and respect.

2) No fighting or hurting one another.

3) If a group leader put their hand up that was a request for silence.

4) what is said in the group stays in the group (confidentiality).

Some General points about grief

1) We are all here because somebody important in our lives has died.

2) After somebody dies we have lots of different feelings, and that is OK.

3) Even though someone has died, we can still have fun.

4) During the next two days we are going to look at what it means when someone special dies.

5) Then the leader explained about the Postbox

Postbox

When somebody special has died, it helps us if we can piece together the story about what happened. Sometimes we don't understand what happened, and that makes it hard. Tomorrow a doctor will be coming to answer any questions which you may have, about things, especially medical things, or about hospitals, that you don't understand. This postbox will be in the room at all times, with a pad, for you to write down any questions that you may think of, so that you don't forget tomorrow.

AIMS 1) To give the child the opportunity to obtain accurate information about medical procedures, to help claify details about their special person's death.

2) To prevent the child from developing a fear of doctors and hospitals by demystifying them, and showing that hospitals are not just places that people go to to die.

EQUIPMENT - A miniture postbox, a pad of paper and a pen.

STORY - "SAYING GOODBYE TO DADDY" Vigna, J (1991)

(20 mins)

This story was selected because it sensitively and simply describes the grief process of a young girl whose father dies in a road traffic accident. It starts with the disruption of the child's normal routine - being brought home from school by someone else with no explanation offered, and how frightening that was. It moves on to the death being explained to the child, by relating it to the natural cycle of life and death seen in flowers, trees and the girl's pet. And then explains what being dead means. The book demonstrates the girl's emotions of anger, sadness and guilt, and embraces these as being normal. The story also describes the funeral ceremony in detail, and the various ways that the little girl says 'goodbye' to her father. Then finally, despite the fears of the girl about the death of the surviving parent, and the continuing sadness, it shows how she valued the momentos of her Father, which reminded her of the good times which they had shared.

AIMS 1) To provide a sensitive, non-threatening introduction to grief, as the activity did not require any self-disclosue.

2) To enable the children to identify with some of the feelings and processes which are experienced by the grieving child in the story.

3) For those children who had not seen their parents lying in rest, or had not attended the funeral, the book attempted to describe these ceremonies and enhance the children's understanding of them.

4) To normalize the children's own grief.

ACKNOWLEDGING THE LOSS (20 mins)

Following the story, it was expected that the communication channels with the children would have opened up a little. So, whilst the group was still seated in a circle, they were all asked to introduce themselves again, and tell the rest of the group who was the important person who had died and any other details or comments about the story which they wanted to add. One of the leaders modelled the disclosure first, adding details of how their special person had died, when, and saying something about this in relation to the story, to encourage the children to give as many details as they wished.

AIMS 1) The children would openly acknowledge their loss, and be able to share it with the rest of the group.

2) This verbal acknowledgement of death would enhance its reality, and amplify the emotions the children were feeling from identification with the story. This would enable some emotional processing to occur.

3) The children would feel supported in acknowledging their loss, as they could identify with the other children in the group,who had all had a similar experience.

DRINK AND SNACK BREAK (20 mins)

AIM 1) After the previous emotionally demanding task, the children were able to have a rest, and be physically active if they wished.

'ALL ABOUT ME' Peta Hemmings (1991)

(60 mins, minimum)

AIMS 1) To encourage the children to think about themselves, and see how the death of someone special may have affected them and their lives.

2) To allow the children to share information,ideas and coping strategies.

EQUIPMENT - This is a board game devised by Peta Hemmings. The board is designed as a brightly coloured jungle,complete with animals, through which the players must negotiate using a footpath. For Winston's group work, a room size version of the board was produced using material, fabric paints and felt sewn in place to represent the path. The 112 question cards were also reproduced and enlarged using one A4 piece of card for each of the uncompleted statements. Two large die and large counters are required.

PROCEDURE - The group of children was divided into the three constituent small groups (introduced during registration). The group mascot bears were used as counters. The game was then played according to the 'rules'. The first team throws the die and moves the corresponding number of steps along the path. Then a question was asked. The statements were fairly general, e.g. 'My favourite colour is... 'If I had a magic carpet I would.....' 'My worst memory from last year is....' etc. The group leaders asked all of the children in the team to say an answer, exploring the answers to elicit more information. The answers were then read to the rest of the group. The next team shook the die and the game continued.

FEELINGS - A TECHNIQUE WITH WATER (60 mins)

AIM - Children often find it difficult to identify and label feelings as they remain a rather nebulus concept until fairly late in development, and even then are very subjective in their interpretation. This demonstration and stimulated group discussion, using a technique from play therapy, enables the child to visualise their feelings, and how they can be 'trapped' by hurt and also symbolises what needs to happen to release them again.

EQUIPMENT - A bowl of water- preferably coloured to make it easier to see, 2 glass jugs, 3 glasses, a tray (to save the carpet), and some cling film.

PROCEDURE - The demonstrator introduces the bowl of water as symbolizing 'loving and caring'. The water is described as coloured because we like to show our 'loving and caring', and we like others to show their 'loving and caring' to us. The jugs and glasses are introduced as representing a family of two adults, Mr. and Mrs. Green (the colour of the water) and their children. The jugs and glasses are then filled ¾ full with water from the bowl. They are described as not being full to the brim with 'loving and caring' as throughout life some sad things happen. The demonstrator asks

Q. "where the family get their 'loving and caring' from?"

A. "Each other."

The demonstrator pours the water between the jugs and glasses, to represent the family sharing their 'loving and caring'. Sometimes families have arguments or problems and some 'loving and caring' gets spilt....demonstrate.

Q. "What would happen if someone, say the Dad died?"

A. "Their 'loving and caring' would go away."

Demonstrate....remove one of the jugs..... he takes his share of 'loving and caring' with him, and the remaining members of the family are sad and lose some of theirs.....spill some of the 'loving and caring' from the remaining jug and glasses.

The Mum would give some of her 'loving and caring' to the children, but perhaps not as much as before, as Mum hasn't got that much left.

Q. "What would happen if she gave it all away?"

A. "It would be all gone, and she wouldn't be able to care anymore"

Now the parent and child haven't got that much 'loving and caring' left, because they have been hurt, and they are scared to share the little bit they have left in case they lose all of it. So, to protect the rest and stop it all running away, they stop sharing it and keep it safe, holding it safe with a skin - 'a suffering skin'..... The demonstrator puts some cling film over the jug and each of the glasses. They all put on a 'suffering skin' as they are so frightened of losing the little bit of 'loving and caring' they have left.Although this skin stops them from losing or spilling anymore of their precious 'loving and caring', it also means that they all have a lot of emptiness trapped inside too.

No one else knows that they have trapped their 'loving and caring' inside, because they can't see the lid - it is invisible. They all sometimes had a smile on their faces, which made them look like they were happy, but inside they only had a bit of 'loving and caring' and a big empty space and they weren't happy at all.

This is 'loving and caring' hidden under their suffering skin.

Sometimes other people help, like relatives or teachers, and they give some loving and caring to the Mum and children.

Q. "But what happens when someone wants to give them some 'loving and caring'?"

A. "None goes in"

.....Demonstrate by pouring some water from the bowl into the jug and glasses.....The 'loving and caring can't get in, but just spills over the suffering skin. The friends will not keep giving them 'loving and caring' as they are losing all of theirs and none is going in.

Q. "So what do we have to do to help this family?"

A. "Take their skin off"

We need to try to heal the hurt a bit, so that they can take off their suffering skin and can start to share their 'loving and caring' again. If we take off our cling film, it means that we may get hurt again - but if we don't take it off, we will always be sad and empty. Sometimes it helps us to keep on our skins but sometimes we need to take them off and allow some 'loving and caring' to come in, and to share some of our 'loving and caring'. We need to judge when it is safe to take off our suffering skins.

SMALL GROUP WORK (1) (45 mins)

AIMS 1) To focus in a more intense and age appropriate level on the children's individual 'stories' of what happened.

2) To encourage the children to share their stories and feel supported and understood by others who have had a similar experience.

3) To normalise their own experience of grief.

PROCEDURE - The children were separated into the age related groups which had been introduced during the registration period.

The groups dispersed into different areas, but all focused on the same topics, e.g. - how they found out about the death?

- did they go to the funeral?
- what did they regret?
- how has family life changed?
- what do they miss most?
- what is their most precious memory?

All of the groups had art materials available. The younger children, were asked to paint or draw a picture of the special person who had died doing something that they used to do a lot, or that they particularly enjoyed doing. Whilst the children were engaged in their art work, a more concrete way for them to express their grief, they were encouraged to talk about their loss.

The older children also used the art materials, but were more able to verbally share their 'stories' and 'memories' of their special person with the rest of their group. In all groups, any unanswered questions about the mode of death were put in the post-box.

ENERGIZER - WARM FUZZIES (15 mins)

AIMs 1) This activity was based in the garden and allowed the children to release some of their physical energy after concentrating on such emotionally demanding work.

2) To allow the children to give and share tokens of friendship with others, which therefore ties up with the feelings exercise conducted earlier, demonstrating that they can still do this without being 'hurt'.

3) To increase the children's self-esteem.

EQUIPMENT - The 'warm fuzzies' were wool pom poms, with a long wool 'necklace' attached to them so that they could be put over the head of another person, along the same principles as a ritual Hawian Houla band. Ideally the number of warm fuzzies available should be 10 x the number of participants.

- The story book "Warm Fuzzies and Cold Pricklies"

PROCEDURE - The warm fuzzies should be hung / hidden in a designated room, or contained garden if the weather is fine. All of them are placed whilst the children are read the story. Then the children are allowed into the 'warm fuzzie land'. They have to find a warm fuzzie, and then present it to another person by hanging it around their neck as a token of friendship. Then they continue to look for another warm fuzzie, being interrupted to receive warm fuzzies that other participants had gathered. Once 'given', the children could obviously keep their tokens of friendship, and most wore them for the remainder of the group, as colourful symbols of their comradeship.

CANDLE-LIGHT CEREMONY (60 mins)

AIMS 1) Many of the children had been excluded from the funeral of their important person and had never said 'Goodbye'. This ritual allowed them to express this symbolically, with the associated thoughts and feelings.

2) The ritual also validated the fact that the individual had existed and died and therefore provided an occasion for confirming the reality of death and physical loss of the person.

3) To give the participants a technique and symbol to allow emotional and physical ventilation upon which they can focus in the future on special anniversaries.

4) To stimulate the expression of memories and feelings of grief within the supportive and contained group situation.

EQUIPMENT - A 'special' candle for each of the participants. In this group, the candles were made in the shape of Winston.

PROCEDURE - Everyone sits in a circle, with the curtains closed. The process was explained to everyone. At all times the unlighted candle was taken to the lit candle of the participant on the left, to prevent the lifting of lighted candles.

The leader started the ritual in order to model the process. She lit her candle using a match saying,

"I am lighting this candle for 'x'.....who died....., and

the thing I remember about 'X' is....."

One by one, each candle is lit until there is a circle of light.

Then a song was sung - e.g. "This little light of mine...."

Then the candles were blown out one by one.

When the room was in darkness, all of the participants joined hands and a 'hand hug' pulse was sent round the circle.

The lights were turned on, and the children de-briefed gently. They were encouraged to light the candle on special occasions in the future, such as, Christmas, the dead parent's birthday, and the anniversary of the death.

STORY - "Badger's Parting Gifts", Varley, S. (1984).

(30 mins)

AIMS 1) Having provoked memories of their loved ones in the ritual, this story focusses on the skills and talents that our loved ones leave us to remember them by.

2) The story describes the process of death and grieving in a simplified, sensitive and straightforward manner.

3) As it involves animals, the story enables the children to relate the experiences to their own in a less intense manner.

4)To allow the children to unwind emotionally at the end of their long day, prior to returning home.

EQUIPMENT - The story book. Milky hot chocolate drinks.

PROCEDURE - The children were given drinks, both for refreshment and comfort purposes. The circle reformed and the story was read to the children by one of the leaders.

The story treats death as a natural inevitable process, where no pain is suffered and the dead animals body is left behind. The characters in the book are sad at the loss of their friend. But by talking together, and actively provoking memories of good times and skills that the deceased had conferred on them,the animals became less sad.

DAY 2

WELCOME GAMES (20 mins)

AIMS 1) To enable the group to re-familiarize themselves with each other and to energize them.

Name game

EQUIPMENT - A soft ball.

PROCEDURE - The participants spread themselves out into a standing circle and threw the ball to each other, saying their name as they did so. Then the game was modified so that the prefixed their name with a descriptive word which started with the same letter as their name, e.g. 'excited Eric', 'talkative Tim'

Chicken

PROCEDURE - All of the participants closed their eyes. The leader chose one member of the group to be the chicken, and whispered this to the individual. The other group members were his/her chicks. The idea of the game was for the chicks to reunite themselves with the chicken.The participants milled around the room until they bumped into someone else. The chicks would 'cheep'. If two chicks met, and both 'cheeped', then they parted and continued to seek the chicken. If the chicken was bumped into it remained silent. The chick would then 'stick to ' the chicken and cease to 'cheep'. The game ended when all of the chicks had found the chicken.

MEDICAL PRACTICAL SESSION (40 mins)

AIMS 1) To educate the children about death, and what being dead means from a medical perspective.

EQUIPMENT - This session was conducted by two staff nurses from outpatients. They brought some stethoscopes, and sphygmamometers.
A life-size outline drawing of a body - created by drawing around one of the children as they lay on a big sheet of paper, and some pens.

PROCEDURE - The outline drawing of the body was stuck onto a board in front of the seated children. They were asked if they knew the names of any of the organs, or internal parts of the body. As they generated the name of an organ, they were asked if they knew where it was in the body, and would they like to come and draw it in. If they didn't know, then the group was asked as a whole. This continued until the major organs had been drawn in. Then the nurse talked through the organs, and corrected any mistakes in positioning or relative size in a very non-threatening manner.

The nurse explained about the importance of the heartbeat, pulse and breathing, and how these all stop when someone dies. She explained how nurses check whether these functions are alright, and demonstrated using the equipment they had brought along to the session. Then the nurses allowed the children to use the equipment, under supervision, on each other, to hear for themselves what being 'alive' sounded like.

DOCTOR'S QUESTION TIME (45 mins)

AIMS 1) To give the children accurate information about illnesses, causes of death or clarify hospital procedures, in order to increase their level of understanding.

2)If the children's understanding of what happened improves, they are more able to emotionally process the events.

3) Accurate information will reduce the magical thinking or fantasies associated with death.

4) To reduce the possibility of the children developing a fear of doctors or medical procedures.

'EQUIPMENT' - A sensitive doctor, who was used to working with children, and explaining concepts to them in linguistic terms that they could understand. The post-box.

PROCEDURE - The Doctor joined the circle of seated children and introduced himself. He then emptied the post - box and began to answer the questions. In reply to each question, he started by saying what a good question it was and then proceeded to try and explain the answer, checking that he was understood by the children. He finished the session by asking the children if they had anymore questions. The leaders were present to ask questions that they thought might help the children understand about how their relative had died, or to prompt the doctor for further information to ensure that the children fully understood.

The questions from the post-box were ;

"Why don't they let children visit their parents in hospital sometimes?"

"Is there a cure for asthma?"

"What causes a coma? What is it? and can the person feel, hear and so on?

"Why do the pipes burst in your brain, causing a brain haemorrhage?"

"Can somebody die because they work too hard?"

"What is a brain tumour?"

"Why didn't the doctors make my dad better?"

"Why isn't there a cure for cancer?"

"Why do some people not want to live?"

"Does your head split open when you have a heart attack?"

"What does happen in a heart attack?"

"Why is it that some people get sick and die before they are old?"

SMALL GROUP WORK (2) (60 mins)

AIMS 1) To focus on their future life without the special person who has died.

2)To start to think about how this event may affect their future.

EQUIPMENT - Art and craft materials made available to all groups.

PROCEDURE - The children were separated into the age-related groups which had been introduced during the registration period. The groups dispersed into different areas, but again all focused on similar topics, e.g.

How will they always remember the person who has died?

What talents or gifts has the person bestowed on them, that they like, and also that they don't like?

If they become a Mum or a Dad, what will they be like?

If they become a Mum or a Dad, what do they think is important?

Have you learnt anything which will help you since attending WINSTON's group?

The younger children completed a 'shield', with four sections, representing these themes, and were encouraged to discuss them with their group leaders.

The groups containing the older children again concentrated more on verbal interaction but also introduced the art material to aid discussion.

TOUR OF THE HOSPITAL (30 mins)

AIMS 1) To show the children that hospitals are not just places where people go to die.

2) To prevent the development of a fear of hospitals.

PROCEDURE - Over the duration of the group the children had made use of the staff dining room in the hospital for lunch. This introduced the notion that the hospital staff regarded it as much more than a building with patients in it. It also provided a social life and was a meeting place for friends, rather like a school institution in the respect that it is made up of more than access to lessons.

After lunch, the children were taken on a whistle-stop tour of the main hospital. They climbed the tower block and saw the different specialist wards and treatments that were available. They walked past the shops and went into the chapel. They visited the maternity ward and then the childrens wards, with the walls covered in bright murals and the children's art work. Finally they popped into accident and emergency. All of the wards are visually very different, and the atmosphere also varied between them, reflecting their different roles.

WINSTON' S WISHES MESSAGE MURAL (45 mins)

AIMS 1) To enhance the children's self-esteem.

2) To encourage the children to share and support each other.

3) To start the process of closure and saying goodbye - the importance of which has been emphasized throughout the group.

EQUIPMENT - A large gold coloured cardboard balloon for each of the children, which had a photograph of themselves in the middle (taken during the Registration period).

- Notelets, on which to write the messages. These had been individualised for each child (the donor), by making them different colours and shapes. On one side of the notelet was written " A message for (child's name), to ensure that none of the children missed out any of the others. Each child had enough notelets to write a message to all of the other children.

- Pens and glue.

PROCEDURE - The children were seated in a circle and given their notelets. They were asked to think about each of the other children in turn, and what they knew about them from the time we had all spent together. Then they were asked to give them a message, or a gift, by writing it onto their notelet which had the receiver's name on it.

When the children had completed writing their messages, they took it in turns to give them to the others, and to receive them. When each child had received all of their 'gifts', they were stuck onto the child's personalised balloon.

CLOSURE ACTIVITIES (45 mins)

At this point one of the leaders went to meet the parents to explain what activities we had undertaken during the group. The parents were also able to share some of their own feelings and reactions to the death of their spouses and the consequent reactions in their children

The children meanwhile engaged in a series of closure activities

Hyacinth pots

AIMS 1) To symbolize the presence of their special person at Christmas, by something living replacing something dead.

2) Demonstrates the cycle of life and death.

EQUIPMENT - For each child, a plain pot with 3 hyacinth bulbs planted in it, with instructions for their care on a label.

- Craft and collage materials and glue.

PROCEDURE - The bowls containing the bulbs were distributed to the children. The principles behind the bulbs was explained. They were asked to decorate the outside of their bowl, perhaps with the name of their special person. Their attention was drawn to the "How to look after me" instructions.

Evaluations

AIM 1) To evaluate the children's level of satisfaction with the contents of Winston's Group work.

EQUIPMENT - Satisfaction Questionnaire (see overleaf).

PROCEDURE - The questionnaires were distributed to the children. Help to complete them was given by the leaders when required, for example, by the 2 children with dyslexia.

'GOING HOME BAGS' (30 mins)

AIM 1) To give the children something concrete to take away from the group and remind them of the work they have completed.

EQUIPMENT - A felt bag for each child, containing ;

1) Teddy

2) Their Winston's Wish message balloon

3) A rock, a smooth pebble and a gem stone.

PROCEDURE - The contents of the bags were shown to the children and explained. The Teddy was a reminder of 'Winston, the bear that cares', the mascot of the group. This was to symbolize comforting and remind them of the group. The message balloon contained the 'gifts' that the other children had to each other.

The rock, pebble and gem stone symbolized the grief process. The leader passed each of the stones around the circle of children, asking them to say a word to describe each one. Then, she incorporated the words generated by the children into her explanation. The cold, heavy rock represented their loss. It was a heavy burden to carry around, and had sharp edges which could often cut into you. However, with time and sharing, the sharp edges gradually wear away, like the bad images and anger, to leave a smooth pebble. It would still always be with you, like the memory of your special person, but wouldn't be as painful to carry. Over the years, as this pebble is worked on, it will become a gem, a place where memories are kept. It is something which you will have to carry throughout your life.

The children were given their bags, photographs and art work.

THE BALLOON CEREMONY (40 mins)

AIMS 1) A ritual to symbolize saying goodbye and 'letting go' of their special person.

2) To acknowledge the reality of the loss.

3) To look to the future without the person who died.

EQUIPMENT - Helium balloons - enough for one per child and another for their parent.

- Two small card tags with ties attached, for each child and another set for each parent and each of the leaders.

PROCEDURE - The children were given the tags, and asked to write a message on each one. On the first tag they were asked to write or draw a message to their special person who had died. On the second tag they were asked to write a wish for the future.

(During the parents' session, they were given two tags each and also asked to complete the above exercise.)

The parents were brought in to meet up with the children, and refreshments were provided. The children then chose a balloon for themselves and their parent. The parents were then invited to attach their tags to their balloon, and share their messages with their child. The children were then invited to read their messages to their parent and also to tie them onto their balloon.

The whole group then made their way to an open site, singing ;

" We are still a family,
We are still a family,
Even though we're changing,
We are still a family.... "

Once everyone had arrived at the site, they formed into a circle,

and after a countdown, the balloons were released.

The party then made their way back to the base to collect all of their belongings and say goodbye to each other.

Six weeks after the Group

PRE_CHRISTMAS CEREMONY

The children and their families were invited to participate in the pre-Christmas ceremony. They were formally invited by letter and asked to bring their Winston candles from the previous group work. They were welcomed as they arrived.

WINSTON'S CHRISTMAS STORY (15 mins)

AIMS 1) To tell the children that it's alright to have fun.

2) To encourage the participants to remember their special person at Christmas, by lighting their candle for example, to make it an overt gesture.

EQUIPMENT - Winston's Christmas Story by Diana Crossley, (1992, in press).

PROCEDURE - The children and their families were invited to sit in a circle whilst the leader read the story, which had been specially written for Winston's group.

CANDLE CEREMONY (30 mins)

AIMS 1) To provide a ritual for the families to acknowledge and remember the loss of their special person.

2) To enable the families to look to the future without their loved one.

EQUIPMENT - A candle for every participant

PROCEDURE - The leader explained the ceremony to the group. She then lit her candle and said,

"I'm lighting this candle for my .....

I remember him/her at Christmas because ....."

The person to her left then lit his/her candle from the lighted one, (i.e. no lifting of lighted candles) and then repeated the statements.

When everyone had lit their candles and the circle of light was complete, the leader read out a poem;

" Pale sun,
Quiet Earth,
Dark nights
Nature's rebirth
Happy songs,
A hug and a kiss,
Tears of sadness,
for people we miss.
Hope for a New Year
shared with a friend.
Things to begin
and things to end.
A light in my life
is burning for you.
A light in my life
is burning for you.

After a few moments the leader said that at Christmas there are usually things that we like, but often things that we don't like. Each person in the circle then mentioned something they were looking forward to at Christmas, and something that they felt that they were not going to enjoy. The candles were then blown out one by one, leaving the room in darkness for a short time.

CHRISTMAS SONGS (15 mins)

AIMS 1) To look to the future.

2) To start to relax from the intensity of the ceremony.

EQUIPMENT - Song sheets

Musical accompaniment (if available)

PROCEDURE - One of the leaders introduced the songs in turn, and started everyone off.

1) "WE REMEMBER"

This was a song written especially for this occasion, and sung to the tune of Kum Ba Yah;

" Now's a special time, Kum ba yah,
To remember you, Kum ba yah.
Now's a special time, Kum ba yah,
We remember, Kum ba yah.

Sad and happy times, Kum ba yah,
Life is changing now, Kum ba yah.
Sad and happy times, Kum ba yah,
We remember, Kum ba yah.

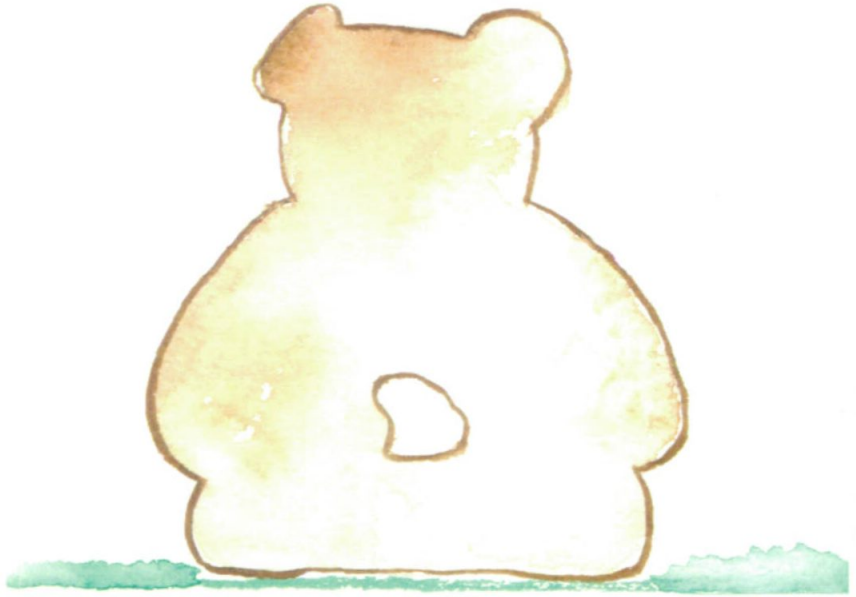
Repeat the first verse again.

2)SILENT NIGHT

3)TWELVE DAYS OF CHRISTMAS

(This was accompanied by actions throughout the song.)

Winstons
Wishes



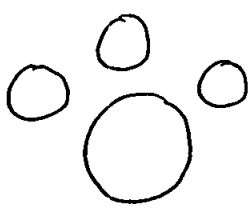

happy
christmas
love from
Winstons Friends
Diana Julie Tim
Pat and Nicky
X

Dear

Winston and his friends would like to send you this message at christmas. At a special time like christmas you might feel quite sad because the person who has died is not here to share it with you, and you may feel that you shouldn't be enjoying yourself. We think that it is alright to enjoy yourself at christmas because this does not mean that you have forgotten the person or that they were not important.

It might help if you can choose a special time this christmas to remember the person who has died. At this time you might like to do something special like lighting your candle.

We hope that you and your family have a good christmas.



CLOSURE ACTIVITIES (30 mins)

Refreshments

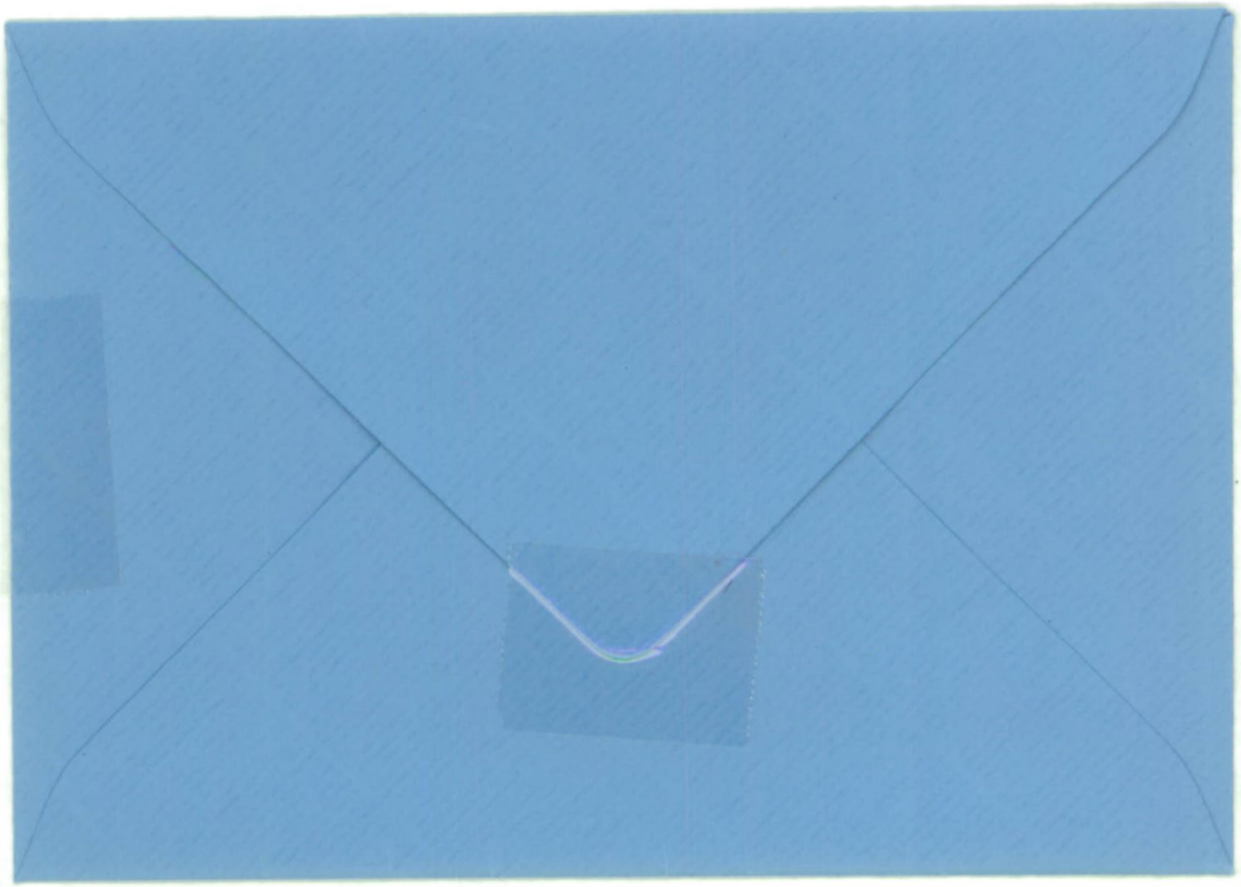
Orange juice and mulled wine were available, with minced pies and bear shaped biscuits.

Warm Fuzzies

The Christmas tree had been hung with warm fuzzies (see earlier for description). The children were invited to collect them and give them as tokens of friendship to others in the room.

Winston's Christmas cards

Each child was given a hand painted individualised Christmas card, featuring Winston, with a message from him inside, (see below).



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